UNIVERSITY OF ALBERTA

Master of Nursing Thesis: The Meaning of

Ethical Practice for the Oncology Nurse

BY

Sandra L. McKinnon

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing

DEPARTMENT OF NURSING

Edmonton, Alberta

Fall, 1994

National Library
of Canada

Acquisitions and
Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale
du Canada

Direction des acquisitions et
des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-315-94980-5

Canada

Name Sandra McKinnon

Dissertation Abstracts International is arranged by broad, general subject categories. Please select the one subject which most nearly describes the content of your dissertation. Enter the corresponding four-digit code in the spaces provided.

Nursing - 0569

SUBJECT TERM

0569 U·M·I

SUBJECT CODE

Subject Categories

THE HUMANITIES AND SOCIAL SCIENCES

COMMUNICATIONS AND THE ARTS

Architecture 0729
Art History 0377
Cinema 0900
Dance 0378
Fine Arts 0357
Information Science 0723
Journalism 0391
Library Science 0399
Mass Communications 0708
Music 0413
Speech Communication 0459
Theater 0465

EDUCATION

General 0515
Administration 0514
Adult and Continuing 0516
Agricultural 0517
Art 0273
Bilingual and Multicultural 0282
Business 0688
Community College 0275
Curriculum and Instruction 0727
Early Childhood 0518
Elementary 0524
Finance 0277
Guidance and Counseling 0519
Health 0680
Higher 0745
History of 0520
Home Economics 0278
Industrial 0521
Language and Literature 0279
Mathematics 0280
Music 0522
Philosophy of 0998
Physical 0523
Psychology 0525
Reading 0535
Religious 0527
Sciences 0714
Secondary 0533
Social Sciences 0534
Sociology of 0340
Special 0529
Teacher Training 0530
Technology 0710
Tests and Measurements 0288
Vocational 0747

LANGUAGE, LITERATURE AND LINGUISTICS

Language
- General 0679
- Ancient 0289
- Linguistics 0290
- Modern 0291

Literature
- General 0401
- Classical 0294
- Comparative 0295
- Medieval 0297
- Modern 0298
- African 0316
- American 0591
- Asian 0305
- Canadian (English) 0352
- Canadian (French) 0355
- English 0593
- Germanic 0311
- Latin American 0312
- Middle Eastern 0315
- Romance 0313
- Slavic and East European 0314

PHILOSOPHY, RELIGION AND THEOLOGY

Philosophy 0422
Religion
- General 0318
- Biblical Studies 0321
- Clergy 0319
- History of 0320
- Philosophy of 0322

Theology 0469

SOCIAL SCIENCES

American Studies 0323
Anthropology
- Archaeology 0324
- Cultural 0326
- Physical 0327

Business Administration
- General 0310
- Accounting 0272
- Banking 0770
- Management 0454
- Marketing 0338

Canadian Studies 0385
Economics
- General 0501
- Agricultural 0503
- Commerce-Business 0505
- Finance 0508
- History 0509
- Labor 0510
- Theory 0511

Folklore 0358
Geography 0366
Gerontology 0351
History
- General 0578
- Ancient 0579
- Medieval 0581
- Modern 0582
- Black 0328
- African 0331
- Asia, Australia and Oceania 0332
- Canadian 0334
- European 0335
- Latin American 0336
- Middle Eastern 0333
- United States 0337

History of Science 0585
Law 0398
Political Science
- General 0615
- International Law and Relations 0616
- Public Administration 0617

Recreation 0814
Social Work 0452
Sociology
- General 0626
- Criminology and Penology 0627
- Demography 0938
- Ethnic and Racial Studies 0631
- Individual and Family Studies 0628
- Industrial and Labor Relations 0629
- Public and Social Welfare 0630
- Social Structure and Development 0700
- Theory and Methods 0344

Transportation 0709
Urban and Regional Planning 0999
Women's Studies 0453

THE SCIENCES AND ENGINEERING

BIOLOGICAL SCIENCES

Agriculture
- General 0473
- Agronomy 0285
- Animal Culture and Nutrition 0475
- Animal Pathology 0476
- Food Science and Technology 0359
- Forestry and Wildlife 0478
- Plant Culture 0479
- Plant Pathology 0480
- Plant Physiology 0817
- Range Management 0777
- Wood Technology 0746

Biology
- General 0306
- Anatomy 0287
- Biostatistics 0308
- Botany 0309
- Cell 0379
- Ecology 0329
- Entomology 0353
- Genetics 0369
- Limnology 0793
- Microbiology 0410
- Molecular 0307
- Neuroscience 0317
- Oceanography 0416
- Physiology 0433
- Radiation 0821
- Veterinary Science 0778
- Zoology 0472

Biophysics
- General 0786
- Medical 0760

EARTH SCIENCES

Biogeochemistry 0425
Geochemistry 0996
Geodesy 0370
Geology 0372
Geophysics 0373
Hydrology 0388
Mineralogy 0411
Paleobotany 0345
Paleoecology 0426
Paleontology 0418
Paleozoology 0985
Palynology 0427
Physical Geography 0368
Physical Oceanography 0415

HEALTH AND ENVIRONMENTAL SCIENCES

Environmental Sciences 0768
Health Sciences
- General 0566
- Audiology 0300
- Chemotherapy 0992
- Dentistry 0567
- Education 0350
- Hospital Management 0769
- Human Development 0758
- Immunology 0982
- Medicine and Surgery 0564
- Mental Health 0347
- Nursing 0569
- Nutrition 0570
- Obstetrics and Gynecology 0380
- Occupational Health and Therapy 0354
- Ophthalmology 0381
- Pathology 0571
- Pharmacology 0419
- Pharmacy 0572
- Physical Therapy 0382
- Public Health 0573
- Radiology 0574
- Recreation 0575
- Speech Pathology 0460
- Toxicology 0383

Home Economics 0386

PHYSICAL SCIENCES

Pure Sciences

Chemistry
- General 0485
- Agricultural 0749
- Analytical 0486
- Biochemistry 0487
- Inorganic 0488
- Nuclear 0738
- Organic 0490
- Pharmaceutical 0491
- Physical 0494
- Polymer 0495
- Radiation 0754

Mathematics 0405
Physics
- General 0605
- Acoustics 0986
- Astronomy and Astrophysics 0606
- Atmospheric Science 0608
- Atomic 0748
- Electronics and Electricity 0607
- Elementary Particles and High Energy 0798
- Fluid and Plasma 0759
- Molecular 0609
- Nuclear 0610
- Optics 0752
- Radiation 0756
- Solid State 0611

Statistics 0463

Applied Sciences

Applied Mechanics 0346
Computer Science 0984
Engineering
- General 0537
- Aerospace 0538
- Agricultural 0539
- Automotive 0540
- Biomedical 0541
- Chemical 0542
- Civil 0543
- Electronics and Electrical 0544
- Heat and Thermodynamics 0348
- Hydraulic 0545
- Industrial 0546
- Marine 0547
- Materials Science 0794
- Mechanical 0548
- Metallurgy 0743
- Mining 0551
- Nuclear 0552
- Packaging 0549
- Petroleum 0765
- Sanitary and Municipal 0554
- System Science 0790

Geotechnology 0428
Operations Research 0796
Plastics Technology 0795
Textile Technology 0994

PSYCHOLOGY

General 0621
Behavioral 0384
Clinical 0622
Developmental 0620
Experimental 0623
Industrial 0624
Personality 0625
Physiological 0989
Psychobiology 0349
Psychometrics 0632
Social 0451

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: Sandra Lynn McKinnon

TITLE OF THESIS: The Meaning of Ethical Practice for the Oncology Nurse

DEGREE: Master of Nursing

YEAR THIS DEGREE GRANTED: 1994

Permission is hereby granted to the University of Alberta Library to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves all other publication and other rights in association with the copyright in the thesis, and except as hereinbefore provided neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatever without the author's prior written permission.

#511 10405 - Saskatchewan Drive,
Edmonton, Alberta, T6E 4R9

DATED Oct 6, 1994

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **The Meaning of Ethical Practice for the Oncology Nurse** submitted by **Sandra Lynn McKinnon** in partial fulfilment of the requirements for the degree of **MASTER OF NURSING**.

Vangie Bergum
Dr. Vangie Bergum
Co-supervisor

Karin Olson
Dr. Karin Olson
Co-supervisor

John Dossetor
Dr. John Dossetor

Olive Yonge
Dr. Olive Yonge

Date September 20, 1994

Dedication

This work is dedicated to the nurses of the Cross Cancer Institute:

past, present, and future.

Abstract

What is the meaning of ethical practice for the oncology nurse? Four experienced oncology nurses were interviewed in order to explore this question. Hermeneutical phenomenological methods were employed to address the stories of practice told by 'Helen', 'Sarah', 'Lynn', and 'Marie'. Key themes related to ethical nursing practice included knowing, timing, maintaining relationships, and standing close to suffering. A central question emerges from this research: Will decision trees (algorithms, care maps etc.) interfere with our ability to detect, to"know", and to respect the rhythm of the cancer patient?

Acknowledgements

I would very much like to thank my thesis co-supervisors, Dr. Vangie Bergum and Dr. Karin Olson, for their patience, their wisdom, and their time. Dr. Bergum's pioneering work in the areas of ethical relationships and nurturance has been central to my thinking prior to, and during this research project. Through her dedication to the experience of both cancer patients and the nurses who care for them, Dr. Olson has provided thoughtful support.

I also wish to thank committee members, Dr. John Dossetor and Dr. Olive Yonge for their valuable questions and contributions. Their expertise in bioethics and communications, respectively, were crucial to this research.

I would like to extend a special thankyou to Maureen Lesiuk for her hours of "transcript typing", and for her friendship and wise counsel.

This thesis, indeed, the whole of my return to school, would not have been possible without the support of my friends and family. To my family: my father, Hugh McKinnon, Shirley Majeau and her wonderful family, Barb, Sharon and Vic, Joanne, and Donna; thankyou for listening (and not listening), and for helping me get through it all. Thankyou, mom; you are with me always.

I also wish to acknowledge and thank The Alberta Foundation for Nursing Research for providing funding, and The Canadian Cancer Society, for providing a Maurice Legault Clinical Cancer Nursing Fellowship for the duration of my program of study and research.

Last, but by no means least, I wish to thank "Marie", "Sarah", "Lynn", and "Helen". Your courage and willingness to tell your stories of getting it "right" and of getting it "wrong" is truly inspirational. Thank you.

Table of Contents

Chapter 1: Introduction and Purpose 9

Chapter 2:Literature Review 13

Support for the Research Topic 13

The Traditional Approach to Nursing Ethics 14

The Contextual Approach to Nursing Ethics 17

Research Question 20

Chapter 3:Method

..... 21

Overview of Hermeneutical Phenomenology 21

Study Participants 22

Data Collection and Analysis 24

Credibility and Rigor 26

Ethical Considerations 29

Chapter 4: Toward A Phenomenology of Oncology Nursing Ethics

..... 31

Marie's Story 31

On Knowing 36

Knowing with certainty: Safety, security, and doing the right thing.

. 38

Knowing so is more than thinking so 44

All knowing is personal knowing. 47

Knowing makes us vulnerable 50

Knowing without certainty: Living the question 54

On Timing 58

Timing, rhythm, and knowing. 59

Timing and particularity.

. 60

Timing and synchronicity 65

On Relationships 71

Knowing when to push (and where and who and what). 76

On Suffering 82

Dissonance and resonance as clues to knowing and timing 88

Chapter 5: The Rhythm of The Patient or The Patient as an Algorithm? 91

References 94

Chapter 1: Introduction and Purpose

Caring for people with cancer has become increasingly complicated. Issues ranging from the proliferation of sophisticated treatment options to the debate over euthanasia place oncology nurses in the middle of an ethical maelstrom. What does this mean for the everyday experience of an oncology nurse? Roy (1989) cites truth-telling, euthanasia, allowing to die, research, and increasingly limited resources as central concerns for health-care professionals who work with cancer patients. While this may be true, the influence of these issues on daily practice is far from clear. The descriptions and adjectives surrounding ethical dilemmas for nurses are discouraging at first glance: powerlessness, moral conflict, burnout, frustration, distancing (Erlen & Frost, 1991). There is, however, more to ethical practice than these dilemmas seem to show; stories of caring and connection speak to the reasons why a nurse would choose to remain in oncology, in spite of the demands of work. Several questions may be asked as we explore the meaning of ethical practice for an oncology nurse. What does an ethical practice look like at two o'clock in the morning? What compels thoughtfulness on the part of the nurse, or, as Benner and Wrubel (1989) question, what "shows up" in the life-world of the nurse as meaningful? What do we mean when we say that a nurse practices ethically or that a nurse has an ethical practice?

If, as some authors argue, nurses are limited in the freedom to act as moral agents within the current health care system, we might also ask whether anything would be gained by inquiry into the ethical experience of an oncology nurse. Yarling and McElmurry (1986) have initiated considerable debate in the literature through their contention that nurses cannot be considered moral agents because of a complex union of

role constraints, social position, sexism, paternalism and powerlessness. It may be, however, the "in-between" nature of nursing, as described by Engelhardt (1985) and elaborated by Bishop and Scudder (1990), that affords nurses a unique ethical perspective. Perhaps the appropriate question is not what would be gained, but rather what would be lost if we fail to examine the experience of ethical practice among nurses. As Benner (1991) asserts, the knowledge of caring and of ethical comportment is embedded in nursing practice and by exploring practice we will find stories that expand possibility and extend moral imagination.

Most of the recent research in nursing ethics has been directed toward the behavior, judgment, or decision making techniques of nurses. Areas of meaning and experience which elude operational definition or measurement are given less attention. Researchers have faced significant methodological limitations relating to the comprehension of meaning within the complexities of nursing practice. Bishop and Scudder (1990), in an effort to begin to articulate a philosophy of practice, turned to phenomenology as an appropriate method of bringing to consciousness "the sense of nursing which is already inherent in practice, rather than imposing meanings on it from outside" (p.5). The authors cite Huston Smith (p.90) as noting that the term "`meaning' itself has these two essential definitions: one referring to the intelligibility of an activity, the other referring to the moral worth of that activity". They argue that "meaning" in the practice of nursing encompasses both, and that to understand nursing practice, one must recognise ways in which these two "senses" of nursing interact and converge.

Bishop and Scudder (1990) devote a full chapter to a discussion of the concept of

"practice". They argue that practice must not be confused with technique or skills, but should be considered as a broader concept, situated within a contextual, historical matrix of caring for those who are ill. In fact, they maintain that in order to answer the question of "what is practice," questions related to the nature of nursing ethics and of the nature of nursing itself must also be addressed. Based on their exploration of these questions, Bishop and Scudder (1990) agree with Benner and Wrubel's (1989) contention that nursing, nursing practice, and nursing ethics are integrally connected.

The purpose of the following phenomenological study has been to explore the practice of oncology nurses in a way that respected the nature and authenticity of their experience. As Lynch-Sauer (1985) states, the goal of phenomenological research is to turn experience into knowledge, through which "the person's lived experience becomes available... in language" (p.97). My own interest in the experience of ethical practice among oncology nurses grew out of seventeen years of working with people who have cancer, most of the time with people for whom death was near. I worked with dying patients who wished to live and with living patients who wished to die, in a society that too quickly responds to the language of detached objectivity, and too easily dismisses the "emotional" concerns of nurses. I have, at times, experienced considerable frustration in my ability to effect change, both at the bedside, and at the larger system level. In part, I have been constrained by language; by my inability to articulate what my practice has lead me to know. The people I have encountered; patients, families and colleagues, each with their own perspectives, have helped me to let go of simplistic conceptions of right and wrong, and to begin to comprehend the complexities of practicing ethically. Through this

study, it is my intention to continue the process of validating and valuing the experience of ethical nursing practice.

Chapter 2:Literature Review

Support for the Research Topic

Several sources in the oncology nursing literature support a decision to conduct research in the area of nursing ethics. Degner (1987) and the Western Consortium for Cancer Nursing Research, in a replication of an American study, used a Delphi survey technique to determine research priorities in the four western provinces. Based on the second round of responses from 143 practicing oncology nurses (out of 300 surveys mailed), members of the Consortium concluded that the development of strategies for preventing burnout and promoting morale ranked highest for research into the experience of nurses. A request for research into helping nurses deal with feelings of grief, loss, and frustration ranked second. The authors noted that results of this study were discouragingly similar to those from a similar study conducted in 1978, suggesting that researchers must begin to respond by investigating the ethical experience of nurses.

In 1989, Bramwell and the London Research Consortium in Ontario conducted a research study designed to identify practice problems, rather than research topics. A survey was used to elicit both quantitative and qualitative information about difficult patient-care problems, as well as the most difficult problems personally experienced by nurses caring for cancer patients. Sending 1,328 questionnaires to a wide variety of agencies yielded a response rate of 43%. Respondents were asked to rank order a list of potential problems and rate them on a scale of one to four for degree of difficulty. The survey was developed by consortium members and pilot-tested by "nursing-staff". The authors reported little variation across all demographic groups for the five top-ranked

problems personally experienced by the nurses, and all five were related to coping issues. The ethics of continuation or termination of active treatment ranked third. The qualitative aspect of the study involved analysing the 1,052 comments received for patterns, plausibility and clustering. In the "coping" category, many comments related to difficulties in dealing with angry patients, multiple deaths in a short period of time, and feelings of hopelessness. In the "control" category of comments, issues involving decision making for treatment options, discontinuing treatment, and "do not resuscitate" orders elicited the strongest comments. The fact that categories were predetermined, and the lack of detailed information regarding development of the survey may represent limitations of the study.

The Oncology Nursing Society (Mooney, Ferrell, Nail, Benedict & Haberman, 1991), a predominantly American organization, surveyed members in order to determine research priorities. The authors noted an interesting difference between this published study, directed toward ONS leadership and nursing researchers, and an unpublished survey of the general ONS membership conducted during the same time period. The general membership ranked burnout and self care of oncology nurses as top priority for research, an area that the researchers ranked seventh.

The Traditional Approach to Nursing Ethics

Gilligan (1987) maintains that the way in which individuals organize self, others, and the relationship between them determines their moral orientation. She describes the traditional, principled approach to these "basic elements" as one of detachment in which moral judgment becomes a process of determining the right thing to do on the basis of an objective, impartial application of a predetermined set of universal principles. Penticuff

(1991) notes that in spite of "internal inconsistencies" in the classic bioethical principles of justice, autonomy, beneficence, and non-maleficence, and "discordant" theories linking them together, they have been taken for granted as ethical imperatives and guides for practice. Indeed, the Alberta Association of Registered Nurses (1987) has published guidelines for ethical decision making that reflect this belief. It is clearly stated within the guidelines that "[e]thical decision-making requires a knowledge and understanding of the principles involved" (p.3). Penticuff, however, argues that the use of principles in a "formula ethics" approach will lead to a distorted view of reality, through which nurses may consistently appear to employ inadequate moral judgment in research studies using only this perspective. DeWolf (1989), for example, while acknowledging that "little is known about the process nurses use to resolve...ethical situations in the clinical setting" (p.77), nevertheless assumes that her study participants have erred by identifying only two options, rather than the "preferred" method of choosing between several alternatives for action. DeWolf concludes that nurses "need" to identify multiple options and recommends that inservice education be provided to this end.

Cooper (1991) contends that most research into nursing ethics has been conducted with the assumption that a principle-based, justice oriented framework is the appropriate paradigm for practice. As well, in an integrative review of studies conducted between 1983 and 1987, Ketefian (1991) found considerable evidence throughout the literature of widespread use of ethical models and measurement instruments based on Kholberg's conception of a hierarchical stage theory of moral development. The problem with this, as Munhall (1983) states, is that a "domino effect of methodological and/or theoretical

fallacies occurs when an instrument derived from a questionably appropriate theory is used to answer questions" (p.44).

Do nurses use the language or structure of principle based ethics in their daily practice, and if not, should the assumption be made that practice would be enhanced if they did? Could a decision made by a nurse be considered ethical if it was based on something other than principle-based ethics? Should we assume that a nurse is at an earlier stage of moral development if his or her behavior does not correspond with Kholberg's or even Gilligan's expectations? If the traditional approach to nursing ethics is insufficient, should research be directed toward uncovering "better" principles, or is a different orientation required? Certainly, we are at a point where we have far more questions than answers in our search for appropriate theories. Jansson and Norberg, noting in their 1989 study of nurses' ethical reasoning that the nurses could easily express ideas and opinions about the care of cancer patients, but had difficulties arranging and applying ethical principles, urged caution in jumping to conclusions. Rather than assume that the nurses lacked capacity for ethical reasoning, the authors recommended that further research be conducted to determine how nurses reason in practice situations.

Although the Canadian Nurses Association (1991) Code of Ethics For Nursing provides a thoughtful delineation of the moral commitments of nursing, the role of the Code in daily practice has not yet been determined. Davis (1991) studied the responses of 27 master's-prepared nurses working in American hospital settings to four hypothetical vignettes involving ethical dilemmas. As well, the nurses were questioned for both their knowledge of the American Nurses' Association [Ethical] Code for Nurses, and for the

extent to which they used the Code in practice situations involving informed consent for patients. Davis found that none of the nurses had knowledge of the Code. A content analysis of the responses revealed that the nurses used four other sources for developing a personal practice code of ethics. Experiences from clinical, personal, research, and nursing school settings were identified as categories of sensitizing incidents. It would be premature at this time, due to the lack of correlational research studies, to assume a direct connection between the Canadian Nurses Association (1991) Code of Ethics For Nursing and routine practice.

The Contextual Approach to Nursing Ethics

Beginning with the work of Curtin (1979) and Gadow (1980) in nursing philosophy and ethics, and Gilligan (1982) in feminist ethics, questions have been raised about the relative roles of principle-oriented and context-based, care-oriented ethics. While ethical inquiry based on the detached ordering of rules and principles is the more widely accepted and familiar method, researchers, philosophers, and practitioners are proposing that a relational ethic of care may be more appropriate for nursing practice (Benner, 1991; Gadow, 1980; Sherwin, 1989; Spreen Parker, 1990; Watson, 1990). Several authors have challenged the traditional approach to nursing ethics through which biomedical ethics were accepted without investigation of their relevance (Cooper, 1991; Fry, 1989; Omery, 1989). There remains, however, a paucity of solid, reliable research studies able to contribute to an integrated theory of nursing ethics (Davis, 1989; Fry, 1989; Penticuff, 1991).

Cooper (1990) acknowledges that "[t]he idea of an ethic of care is a recent one

(and) [n]o claims are being made that an ethic of care constitutes a complete ethical theory" (p.211). Cooper's (1991) study investigating the use of principle or care based ethics for eight nurses showed that both perspectives were used in practice. She noted that "while principle-oriented ethics and the ethic of care are depicted in the literature as distinct frameworks, they clearly do not always represent discrete experiences for nurses" (p. 24). She suggests that we must not overlook the richness of practice in our search for a theory that will "simplify the complex," and strongly advocates the use of narratives as a method of approaching the holistic context of the nursing experience.

Cohen and Sarter (1992), in a recent phenomenological study, explored the meaning of oncology nursing for nurses caring for cancer patients. Interviews with 23 nurses working in one large cancer hospital were analyzed using phenomenological techniques of thematic search and analysis. All 23 nurses were women, with a mean age of 42 and a mean length of experience in nursing of 13 years. Most nurses identified themselves with various specialty areas within the hospital, such as paediatrics or critical care, rather than as oncology nurses, and most worked at the hospital for reasons other than its oncology focus. The nurses were asked to describe stories of `critical incidents', following Benner's technique of clinical exemplars, that held the essence of oncology nursing for them. Most descriptions focused on the physiologic needs of patients. In contrast, when asked to discuss the difficulties of oncology nursing, the stories focused on "human interactions and relationships... including conflicts with peers and physicians, poor staffing, unexpected crises, and patients' suffering and death" (p.1485). Limitations of the study, as reported by the authors, included interviewing nurses chosen by hospital

managers and conducting the research in a single institution. They noted, however, that their study results indicated a need for nurses to have a "forum for discussion of... sensitive, stressful, or emotion-filled experiences" (p.1486). Investigations regarding the meaning of ethical practice for oncology nurses would therefore be indicated.

Jameton and Fowler (1989) point to the difficulties inherent in conducting research into ethics and morality. They describe a tension between the "real" or descriptive ethics and the "ideal" or prescriptive, universal components of ethics, with the real being judged by the ideal at the same time as it informs the ideal. They advocate discussions with clinical nurses to identify examples of the ways in which nurses handle ethical concerns, as a way of informing the "ideals" of principled ethics and relationships.

The stories of experienced and reflective nurses are beginning to be recognised as rich descriptions of practice that may lead to new levels of understanding (Benner, 1983, 1985, 1991; Benner & Wrubel, 1989; Davies & Oberle, 1990; Levine, 1989; Spreen Parker, 1990). Webster (1991) challenges nursing to develop the language of practice as clearly and articulately as possible, in order to avoid "the disturbing effect of having others distort our experiences as they name them" (p.118). Naming and describing the phenomena associated with ethical practice in words that have not been misinterpreted or distorted is essential to the ability to hold onto the power inherent in the language.

Benner (1991) cautions that "increasingly... our communication is shaped by technical, analytic reporting of the `objective' facts and measurable obervations" (p.19). One wonders if this reflects an attempt by nurses to find a voice in the dominant language of the age. As Yeo (1989) states, "rather than trying to speak the language that happens to

be authoritative, one should learn to speak unashamedly in one's own voice and to celebrate one's difference rather than apologize for it" (p.41).

Research Question

The literature supports research directed toward the ethical experience of nurses. The specific research question is: What is the meaning of ethical practice for the oncology nurse? Related questions are: (a) What is it like to practice nursing in an ethical way? (b) What is it like to practice nursing in a way that is not ethical?

Chapter 3:Method

Overview of Hermeneutical Phenomenology

Benner (1983) maintains that behavior studied out of context will be as meaningless as a word studied apart from its sentence. She argues for an interpretive strategy of synthesis, such as phenomenology, as the appropriate method for investigating practical knowledge, rather than a reductive, purely analytical approach. The goal is to reach an understanding of nursing practice that can be comprehended by others within a shared world of meanings. For example, Benner contends that a complex concept such as `empathy' must survive both the description, and an interpretation of the description. It is therefore crucial for the practitioner to provide the listener with a view of empathy that contains the full richness of the experience. Van Manen (1990) contends that phenomenology is the study of essences; not in some mysterious, esoteric sense, but "as a linguistic construction, a description of a phenomenon" (p.39). He adds that:

> a good description that constitutes the essence of something is construed so that the structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way. (p.39)

The appropriate research method for reaching into the essence of the meaning of ethical practice for an oncology nurse is phenomenology.

Bergum (1991) explains that phenomenological research is conducted in order to "`interpret and understand' rather than to `observe and explain'." She adds that "stated in a

simple way, phenomenology has to do with description of experience, and hermeneutics with interpretation of experience" (p.56). Leonard (1989) defines hermeneutics as an ancient discipline predicated on the recognition that "understanding human action...involves an interpretation by the researcher of the interpretations being made by those persons being studied" (p.50). Language is the tool through which understanding is possible. Accepting that it is not possible to reach an objective "knowing" of another's experience, Leonard explains that the researcher seeks to understand everyday practice, while preserving context and meaning. In hermeneutical analysis, she adds, the researcher begins with a question (what is the meaning of ethical practice for an oncology nurse?), and proceeds with an exploration of one or more nurse's descriptions. The researcher then analyzes the "whole" for new perspectives, uses the new understanding to examine parts of the story, then reexamines the whole with insight gained from the "new" understanding. "The interpretive process follows this part-whole strategy until the researcher [and participants are] satisfied with the depth of [their] understanding" (p.51).

Study Participants

Registered nurses were recruited from among all those currently employed at a large western Canadian cancer institute. Notices were posted in all of the appropriate areas inviting nurses to participate in this research study through sharing stories about their experience of ethics in day to day practice. Although there were no specific ineligibility criteria, the nature of phenomenological research requires that participants be able to describe their experiences with considerable detail and reflection. As a first step, I discussed the nature of the study with each of the nurses who expressed interest in

participating. This initial conversation was not taped. During this conversation, the process of ensuring that consent for this study would be fully informed began. Potential study participants were able to ask questions about the nature of their participation. In essence, both researcher and participant were able to interview each other. All participants were asked to review and sign the consent form (Appendix A) and were interviewed once.

Four nurses agreed to participate in the study. "Helen", "Marie", "Lynn", and "Sarah" have not been identified beyond very general demographic data; all are female, all are over thirty, and all are experienced oncology nurses, having worked with cancer patients for several years as both staff nurses and in supervisory or managerial capacities. I have purposely avoided details regarding the identity of the nurses who participated in this study for two reasons: to maintain confidentiality, and to facilitate reader identification with the stories described. It is hoped that the stories that have emerged through this research will be recognised by oncology nurses as "their" story, rather than stories of any particular nurse.

The number of participants in a phenomenological study is generally lower than in other qualitative designs, in order to keep the data at a manageable level (Field & Morse, 1985). As explained previously, the point is not to determine objective truth, but to achieve as thorough an understanding as possible of the perceptions of a few reflective nurses who are able to articulate their experience in a partnership with the researcher. Study participants were not "interviewed"; rather, they were engaged in conversation. This approach, recommended by Bergum (1991) and van Manen (1990), "implies a discussion and best captures the attitude of [the] interaction" (Bergum, p.61). Questions used to

begin the conversations included:

-can you tell me stories where you felt in conflict between what had to be done and what was done?

-can you tell me stories of situations where you felt really good about what you did - things turned out well?

-can you tell me stories of situations where you would have liked to have done things differently?

-when you say you have done the right thing, what do you mean?

Data Collection and Analysis

It is appropriate to discuss data collection and analysis at the same time, because of their inseparable nature within a phenomenological study. Taped conversations were conducted with each study participant, at their convenience. Each session took place over about ninety minutes; three were held in a conference room at the Bioethics Center, and one in an office at the cancer institute. Each participant was formally interviewed (taped) once. Informal discussions with each participant regarding study findings were held as analysis progressed.

Leonard (1989) describes several interrelated processes for analyzing data, including searching for themes and for paradigm cases, "strong instances of particular patterns of meaning" (p.54). Although as Leonard concedes, the lived world of another can never be explicitly known, and "although we must live with a plurality of interpretations of meaning, we can narrow things down" (p.54). Van Manen (1990) lists six generally consecutive research activities as a loose framework for conducting

hermeneutic phenomenology. Beginning with the identification of an interesting phenomenon, the researcher investigates lived experience and reflects on the essential themes that characterize the phenomenon. This is followed by writing and rewriting in an effort to clearly describe the phenomenon, while maintaining a balance within the research context between the "parts and whole". Van Manen (1990) notes that "a certain openness is required in human science research that allows for choosing directions and exploring techniques, procedures and sources that are not always forseeable at the outset of a research project" (p.162).

The taped conversations of each of the four participants were transcribed verbatim. Each transcript was reviewed for accuracy, and then read and re-read for impressions and a search for meanings. Certain words came forward as central to many of the stories; words such as "knowing" and "pushing". Other thematic notions were less explicit. The notion of timing and synchronicity, for example, came forward after numerous readings. During the analysis, I continued to search through literature for more stories of ethical practice, as told by nurses, and for stories of what it was like to have cancer, to be ill, as described by patients and family members. Considerable time was spent "journalling" my thoughts and impressions about ethical practice and the stories I'd been told. For example, one entry read:

> Levine (1977) states that "the willingness to enter with a patient that predicament which he cannot face alone is an expression of moral responsibility; the quality of the moral commitment is a measure of the nurse's excellance" (p.845). Does `ethical' imply that one will go above and

> beyond the call of duty? I can't equate ethics with heroism, unless we can also understand in this context that ethics is the everyday experience of the nurse and every nurse a daily hero.

This entry lead to an exercize in my journal consisting of a line by line exploration, through each transcript, for the ethical meaning behind each action, each statement. For example, within "Marie's Story," I found the following:

Ethics Means:

1) remembering patients and learning from our mistakes with them

2) pushing, even when I am unsure of myself; not backing off

3) standing by someone whose pain exhausts me

4) trying and trying again

5) comprehending the pain of other team members

6) moving through (beyond) fear and anger

This exercize was very helpful for opening up the stories and beginning the process of writing and re-writing. Themes emerged during both the writing and through several discussions with my committee co-chairs.

Credibility and Rigor

Rather than the objectivity, validity, and reliability required of quantitative research, Sandelowski (1986), and Krefting (1991) cite Guba's criteria of truth value, applicability, consistency, and neutrality as more appropriate measures of rigor for qualitative methods. Sandelowski maintains that a study must be credible to people who have experienced the phenomena, and recognisable to people who come to the experience

after having read about it. She adds that a study is "credible when it represents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognise it from those descriptions or interpretations as their own" (p.30). Leonard (1989) agrees, adding that applicability can be attained in spite of the small sample sizes, through a description of paradigm cases that shed light on the experience of people outside of the study situation.

Sandelowski (1993) addresses the difficulties inherent in "represent[ing] multiple realities in a way that still remains faithful to each [study participant's] reality" (p.5). Through her discussion of the range of methodological errors that may occur when researchers rely too closely on participant consensus with study findings, I decided to inform my participants of my findings, but not re-interview them as a way of implying "proof" of the trustworthiness of the analysis. As explained by Sandelowski, the nature of many qualitative studies demands that responsibility for the credibility of the findings rests with the researcher. The ultimate test of validity will reside with practicing oncology nurses. If, in reading the results of this study, they are able to recognise their own reality, perhaps "known" but not articulated, then the study will have been a success.

The close involvement of the researcher in phenomenological investigations requires particular attention. Van Manen (1990) describes the method of bracketing, whereby the researcher acknowledges and sets aside their opinions and beliefs about the topic; to be aware of them but not ignore them. Bergum (personal communication, Feb. 19, 1993) suggests, however, that the neutrality required of most qualitative and all quantitative research is neither possible, nor to be expected, for phenomenology. The

research question itself, notes Bergum (1991), which compels us to search for understanding, demands "a kind of involvement in research [that] allows no detachment" (p.57). She adds that our orientation to the question must not become wholly subjective and introspective, but rather, "self-questioning about the nature of one's involvement" (p.23), with space for both one's own experience and the experience of others.

As I have listened to the stories described by Sarah, Lynn, Marie and Helen, and studied the transcripts I have done what every other nurse will do: I have linked their stories to my own, compared their practice to mine. While I have come to agree that `bracketing' my own perspective is neither possible nor desireable, it remains essential that I be as honest and clear as possible about my own beliefs. What do I think ethical behavior is or should be? As I listened to my participants, there were times that I found myself wishing they had gone further or done things differently. There were times when I cheered their decisions. How could I avoid being judgmental and exercising my own determinations of what was right or wrong?

In the end, I followed the path of phenomenological researchers and philosophers who have shown the way. I opened myself to the question itself and to the stories told by my participants; I trusted that what they told me was the truth of their experience as told to me at that time, in that room, on that day. This acceptance and trust was essential to my ability to "hear between the lines," to meet my participants and their stories with complete respect. As Knaack (1984) notes, citing Colaizzi, phenomenology must be grounded in the assumption that experience itself is authentic and "objectively real for myself and others" (p.109).

In essence, I have just described my own belief about what it means to be ethical: To respect is to trust, to trust is to be open, to be open is to hear, to hear is to believe, to believe is to respect. It is from this perspective that I received what was told to me.

It would be appropriate to address the ability of this researcher to conduct a phenomenological study in a familiar work setting. I have worked at the cancer institute for several years and in a variety of positions, most recently with out-patients being treated in the radiotherapy department. The fact that I have a long history at the same hospital as the study participants may have increased both my sensitivity and my access to the stories told by the nurses. I believe that the possible benefits (access to potentially very rich information) outweighed the risks (losing perspective).

Ethical Considerations

Bergum (1991) states that the women who participated in her phenomenological study described a benefit from the experience. "It raised their awareness of what they were going through and resulted in reflection that may not have occured outside the research environment" (p.67). This represented one possible outcome for participants, but not the only one. It is also possible to experience anxiety and self-doubt when reliving situations of ethical practice. Nurses who agreed to participate signed a consent form (Appendix A), but the consent for this study was a process that continued throughout. Participants were encouraged to disclose only that with which they felt comfortable. Participants were informed that they could withdraw from the study at any time. This could be accomplished by asking the researcher to turn off the tape recorder and end the interview, or by withdrawing consent for transcription or analysis of the interview.

Participants will not be identifiable in any published or unpublished study results. While confidentiality will be provided, anonymity cannot be guaranteed. A master list linking participant's names with identification numbers (as noted below) has been stored separately from transcripts and tapes in a locked cabinet. Data were available to the investigator and committee members, identifiable by ID number only. A transcriptionist also had access to information and agreed to maintain absolute confidentiality; as an employee of the hospital, she is obligated to do so. Transcripts and tapes will continue to be stored in a locked filing cabinet accessible only by the researcher. The tapes will be erased upon completion of the study. Transcripts will be kept in a locked cabinet for seven years, in keeping with University of Alberta research policy. If secondary analysis is undertaken, ethical clearance will first be obtained.

Chapter 4: Toward A Phenomenology of Oncology Nursing Ethics

The following story is central to the findings of this study and as such has been included in its entirety. Several key concepts such as "knowing," "pushing," "relationships (with patients, doctors, and oneself)," "being there (standing close to suffering)," "living through," "learning the lessons again," "getting past the fear and anger," etc. are represented in this story. The patient described in the story was undergoing palliative care.

Marie's Story

...it has had such an impact forever that I will never forget it. And the names, and the place, and the smells are just about as vivid today... as they were - I guess it's thirteen years ago... [T]here was a patient named Mark (pseudonym) who [had] a lymphoma and apparently he had been coming to [our hospital] for ten years, so it was one of those long cases that had been in remission... and things were really good [but he had relapsed] and you know after ten years when they relapse they are in big trouble quickly. Mark came in and he was in big trouble... he had been getting some chemotherapy and some Vincristine and other stuff and he came in because he looked like he was ten months pregnant and he had a terrible neuropathy. What Dr. Ness (pseudonym) thought was that [Mark] probably had a neurogenic bowel, he just didn't have any peristaltic movement, probably from the Vincristine; he was just so constipated and so [the orderly] and I were giving him enemas. As the night went on we [were] putting this man through pure hell because he wasn't really constipated - there was something else going on - something else was really wrong.

He is screaming in pain, he is yelling, his bowels aren't moving, he is not even

moving air and he is so distended - he has this huge belly and his legs are so distended and swollen and you know we're giving him an enema and setting him on the commode, dragging him in and out of bed, and this isn't really working and it's one of those glorified - they used to give molasses and all sorts of stuff... So, as the evening went on, I was fairly new here, and everybody knew that you never push too hard with Dr. Ness... but I couldn't stand it because this guy was in pain and so I would say "can he have something more for pain?" and [Dr. Ness would] say "well", and eventually I'd get him something more for pain and give him a little bit of Codeine and... it was nothing. I didn't know enough about pain management to really push but I kept kind of pushing, and I was amazed at how I kept kind of pushing but about 10:00 that night I realized that I had not taken care of any of my other patients, I had been with Mark all night, and the pressure of listening to him ask for something for pain, of being in such terrible pain, was absolutely exhausting. I was just terribly exhausted; I just wanted to run out of that room and scream "would you do something". I've got to do something, I've just got to do something and I went into the room and I said "I've called Dr. Ness again, I'll keep trying, I'll just keep trying," and he said "get me a gun". (Marie gets choked up) I have no idea why I'm doing this now, I haven't cried about this for years... He said "get me a gun - I'll shoot myself". I thought he'd die too, I honest to God thought he was going to die from the pain. Now I've had pain in my life since that time, and I think you almost want to die - you do want to die from the pain. He really wanted to die, the pain was so bad, and I'm looking at him and he say's, "Marie, just get me a gun and I'll do it myself," and he wasn't kidding. And I couldn't get him a gun and I couldn't help him. And so, one

more time I go out - you know, you always leave the room thinking "I'll talk to the doctor, the doctor will do something" - and I went out and I pushed again and Dr. Ness came up and he ordered a little bit more, and I gave him a little bit more. It was midnight and Dr. Ness was leaving the ward and he said "Aren't you going home, Marie?" and I said "yes, eventually". And he said "well, have a good evening" and I said "I don't think so...I will if Mark will" and Dr. Ness didn't say anything and I was furious at him. Just furious - just overwhelmingly upset - and I started to cry. I think I was crying with absolute frustration and I went home that night with this not resolved, knowing that this is a patient in terrible agony and I am supposed to be somebody who can at least alleviate or help in some way and I didn't help him worth one damn. I went home and I went back to work the next day at 3:00 and [the head nurse] met me at the elevator and said that Mark died at 4:00 in the morning, and I thought okay, "I won't cry, I won't cry, I'll just go in and get report and I won't do anything". I went into report and everybody was there and it was quiet and I couldn't look at anybody. They said Joan, the counselor, a psychologist, is coming to talk to everybody and I knew why - oh yea, you know, they're always going to help us - we're going to have a little debriefing so we all feel better. And I thought, well that's fine, I'll just sit here. I'm not saying a word, though, I'm just going to sit here. And I just sat there in the corner and I looked down and I just couldn't talk. I thought "I can't cry, I won't cry," and she started to talk to everybody and one of the nurses [who] had been there much longer than me said - she was crying and I wouldn't contribute to this conversation, I just couldn't do it and I didn't want to, I was just angry - and she said "you know the worst thing about this? This man has been coming for ten years and when

he really needed us we weren't there". And it dawned on me that that was true, that we weren't there, but not only that, I wasn't being there for those nurses who knew Mark a heck of a lot longer than me; a lot longer and were a lot closer to him than I was. So I went through a night of agony and I thought it would kill me and it did kill Mark, and they went through 10 years with somebody who counted on them, and they had to live with that. So, I did start to talk, and it actually was very helpful. We all had a cry and shared, and I did talk, and I felt a bit better. But I walked out of report and two people came up and said "Dr. Harvey wants to talk to you on the telephone and Dr. Ness is here to see you". I went to the phone to Dr. Harvey and he said "Marie, I just wanted to tell you that we had an immediate autopsy and... why Mark had died suddenly like that in severe pain" ... he had a ruptured spleen and the whole business from the pressure of this distended bowel. And so without any discussion, Dr. Harvey had recognised that we had a need as nurses to know what happened... what could we have done... and he let me know right away. The next thing that happened was Dr. Ness was standing there very quietly and he said "Marie, I want you to know, I didn't know what more to do". And he said "I'm very sorry about Mark and I know you are too." And we said nothing more, and it was like he said: I know you were so mad at me. I was never going to forgive him, I mean never. I was going to hold him accountable forever. So, I realized two things. I realized that he was suffering too, as a physician. He was losing somebody that he knew for ten years, and that he seemed to have no control over what was going on either, and that, too, helped me get through that anger. In fact, it's gone, just gone. But what I learned from that time was that I was never, ever, ever, going to be in a position where I

didn't speak out immediately [to say] "please do something," "do something more," "they need more analgesic," "it doesn't matter, you are not going home, I am not going home, nobody's going home until something can be done - this is not the way people die". And I don't care who I upset, I don't care who I anger, I don't care if it's God himself (and Dr. Ness was at that time) - if you anger him then you won't get anything, right? (laughs) Isn't that right? [I] already knew not to push him too hard because you won't get anything. And so that's what I did - I didn't push as hard as I needed to and as I wanted to, and maybe even as I should have. So I promised myself I would never do that again. [But] I <u>have</u> done it [again] where I backed off and still to this day I will go "I did it again"! I backed off and I always regret it. So the times that I think "oh, don't make waves, don't push" are necessary, but there are times in my life where I think I've learned something... because it was such a dilemma for me and it hurt so hard that that will never happen again. But it does happen again - now I've come a long ways - but every once in a while I have to learn... I still have to live with the fact that I am a human being and I still back off when I shouldn't. I don't know if I'll ever - I could live to be 100... I always use my age as an excuse now, that I [can] say that I get to push because I'm old enough, and because I don't care like I used to. I simply don't care about [the doctor's] response. ...I care about that person (the patient). ...I don't care if they're angry at me, if they think I'm a nag, if they think I'm a pain in the butt, if they think I'm a bitch - I don't care. I truly don't care. ...[But the] physician... might be the only physician [available].

(added from p.4, L34-36) ...you can be a great nurse through the good times and through the bad times; you can be a good friend...but when the crunch comes is when

you've really got to be there and that is not the time to back down".

On Knowing

> Rainer Maria Rilke: Were it possible for us to see further than our knowledge reaches, and yet a little way beyond the outworks of our divining, perhaps we would endure our sadnesses with greater confidence than our joys. For they are moments when something new has entered into us, something unknown; our feelings grow mute in shy perplexity, everything in us withdraws, a stillness comes, and the new, which no one knows, stands in the midst of it and is silent. (1992, p.233-234)

Marie's description of her nine hour shift is framed by what she knows and what she does not know. She describes "one of those cases... you know after ten years when they relapse they are in big trouble quickly." "...everybody knew that you never push too hard [with Dr. Ness] but I couldn't stand it because this guy was in pain..." "Knowing that this is a patient [who] is in terrible agony..." "...I didn't know enough about pain management to really push but I kept kind of pushing."

What does knowing something mean for ethical practice? Marie's dilemma with her patient is a complex story of her predicament of knowing/not knowing the right thing to do as she lives through the experience. It is only after thoughtful reflection that she is able to make sense of the situation and find meaning. For example, Marie acknowledges that she relied too heavily on the general "knowledge" of this doctor. She learned an important lesson through this experience: "I promised myself that I would never do that again," meaning that she would continue to push as hard as she could. Marie also learned

something about the limits of what a doctor may know. As Frank (1991) states, "In hospitals... the physician is assumed not only to know all but to know more than he says" (p.56).

For Marie, moral growth was precipitated by a painful experience through which she was able to negotiate (find a way over, a path through). She described her ordeal on several levels of knowing: cognitive, emotional, intuitive, and visceral. Marie knew that:

1) the patient was in terrible pain.

2) "something else was really wrong," but she was new and lacked experience in this area.

3) you did not push this doctor too hard without risk to self or to patient (through physician anger or abandonment).

4) she was exhausted and wanted to run, but knew that she had to "do something.."."I'll just keep trying".

What Marie did not know, while she was living through her shift, was how to make the experience less painful for Mark, for herself, or for Dr. Ness. Nevertheless, she did not abandon Mark physically or emotionally. She witnessed his suffering and suffered in the process, doing the best that she knew how to bring him some relief.

Black (1993), in an essay "Caring in Hellish Places" (about a Neonatal Intensive Care Unit), articulates her own experience of knowing (p.132):

> Nursing at its best is to experience with others the most important moments of human life - birth and death, hellos and goodbyes, beginnings and endings. Yet with the triumphs of spirit and body over illness and death

> comes the certain pain of knowing: knowing that some patients will die and that some will not be allowed to die, knowing that for some I will cause pain in order to heal, and for others I will be unable to relieve their pain. I was required to confront my own pain in nursing, and the pain of those around me...

Knowing with certainty: Safety, security, and doing the right thing.

Knowing some things with certainty is crucial in the care of people with cancer. It is vital that caregivers know how to administer chemotherapy safely, know the right dose of narcotics... know how to get a doctor's attention when "something is wrong" but not empirically accessible. Oncology nursing is a specialized area of practice, demanding a credible knowledge of the disease process and treatments. Cancer nurses spend hours at the bedside, in the clinic and on the phone with patients and families, and come to know them in ways that other healthcare workers will not. This knowledge, coupled with a memory of all that could go wrong, has gone wrong for another patient, another shift, can lead to a clear conviction about the right thing to do. As Helen notes "...we're known as a pretty aggressive lot...we can suggest [and] usually get what we think is appropriate" (p.6,L.32,33).

Lynn considers rules and conventions to be foundational to ethical care. Employing maxims such as "[when] a patient has a respiratory or cardiac arrest and you don't know [their code status], then you code them, or you call the code team" (p.4,L.6,7), Lynn initially appears to value certainty in patient care decisions. She describes the concern expressed by staff who had revived a patient from another hospital by suctioning out a

mucous plug, only to find a DNR order buried in the chart. Lynn thought that under the circumstances, "we did the right thing by coding him here, but there were quite a few in the group [who] didn't think that" (p.4, L40-42).

Yet, in spite of her support of the rules, Lynn voices some reservations about "living wills" and "do not resuscitate (DNR) orders" since they might presuppose certainty in care situations when uncertainty exists. Few ethical issues raise more debate in hospitals than the matter of DNR orders (Yarling & McElmurry, 1983). The question of when and how, or even whether, patients should be approached for a decision about resuscitation has not yet been settled, although most institutions provide an illusion of certainty through concrete rules and policies addressing the issue (D.Wilson, personal communication, January, 1993).

Helen illustrates the difficulties that can occur when the code status of a newly admitted patient has not been addressed:

> *...at 6:00 in the morning I found her, well really, dead, but we called a code because there was no... there had been no orders... at the time we didn't know that she had brain metastases and that her days were very numbered anyway. So we called a code and the supervisor called her husband. Unknown to us, the husband must have lived across the road because he came in and found us... doing CPR and all of those things, and he was just absolutely uncontrollable. I mean, he wasn't ugly with us, but he just... this is 6:00 in the morning...* (p.17,L.5-11)

Helen notes that the physician on call had never seen the patient before, and that her

admitting physician, when contacted by phone, told them about the metastases and called off the code. In this case, hospital policy coupled with poor communication by the admitting physician and a lack of knowledge about the patient's disease status and about the wishes of the patient and family, led to a dreadful experience for both staff and family. In many cases, Helen states, the nursing and medical staff will have the benefit of time (to get to know the patient and family) and experience (having witnessed similar episodes) to determine the "right thing to do" before a crisis situation occurs.

There is a particular certainty implied by a DNR order; the certainty that death will ultimately prevail. In the death denying culture of North America, the certainty of eventual death is anathema. Helen considers "full support, no CPR (no cardio-pulmonary resuscitation)" orders to be the "best of both worlds" for the flexibility they afford:

> *...you can do absolutely all that you can to make the patient comfortable and even prolong life, but we're not going to go through this CPR with all its attendant horrors and especially when you've got bony metastases, you know, and you fracture ribs and rupture livers and all this kind of thing...* (p.18,L.15-10).

Another kind of certainty is to be found in the blood tests, scans and x-rays performed on cancer patients; tests yielding empirical knowledge that may begin to appear more "real" than the patient himself. Frank (1991) describes "being colonized as medical territory and becoming a spectator to your own drama--you lose yourself... finding that the lab results rather than your body's responses are determining how you feel" (p.56). Curiously, there is an implication that an objective "knowing" of someone's body is

integral to true healing or will afford protection from illness or death. Marie jokes about this:

> *She had her x-ray and her wrist isn't any better - don't you do a blood count to make their blood better? ...it says right on the headlines "Doing self breast examination can keep you from dying." I have a mammogram every year so how could I possibly get breast cancer? (p.9,L37-40)*

The absurdity of mistaking an objective measurement for more than it is, imbuing it with exceptional meaning, is not lost on the study participants. "[T]his is not just a body with a low oxygen sat[uration]... this is a woman with family and children and, you know, they may not want all this performance with their mother" (Helen, p.9,L.34-36). Helen describes protecting patients from undertakings that promise to yield more numbers rather than more comfort (p.10,L.36-42):

> *...I mean even an x-ray is an invasive procedure if it means the patient has got to be moved, with a multitude of tubes and in pain, down to the X-ray Department and back...if it's not necessary or it's not going to benefit the patient...and sometimes [if] you call the doctor, you know, well they'll order a chest x-ray and lab work... just sort of automatically rather than thinking about "what's this going to show us and are we going to do anything about it if we know?"*

For nurses familiar with their historical powerlessness to ignore an order given, it may seem prudent to avoid contacting a doctor unless the possible benefits outweigh the burdens for a patient. This has lead, in my experience, to such past practices as "slow

codes" where even the doctors could be complicit in the efforts to avoid a cruel or prolonged ending to the life of a patient.

Does knowledge of what to do and knowing that what we are doing is "right" diminish the possibility of repeating the sort of experience described in Marie's story? Helen recalls caring for a patient with "terrible" pain throughout his body from ascites and edema. To minimize his suffering, his wife encouraged Helen to "please give him as much as [she] could," which Helen did without reservation, having obtained the appropriate medication orders. "I felt really good about that, that [his wife] felt part of the decision to do this, to keep giving [the medication], and I think it gives the relative a feeling of some kind of control... they don't want them to suffer" (p.4,L.11-20). In this situation, a peaceful death was achievable; both as a result of a technical understanding of pain control options, and because patient, family, and caregivers were in agreement. Both Marie (p.6,L.1-3) and Helen (p.16,L.30-32) agree that knowledge about pain control has increased considerably. As Marie states, nurses are "much more accountable and have much more confidence in what we're doing" (p.6,L.3).

If certainty is possible, one might turn, with some confidence, to regulations, standard procedures, even Codes of Ethics, to find the information necessary for doing the right thing. Strategies could be developed for quick retrieval; recipes for action that avert trouble. Why, then, is it so difficult when one is "living through" many practice situations to determine what is right? Will knowing the rules (ethical principles, for example), knowing the facts, knowing the patient and taking sufficient time ensure that the patient's wishes will be respected or that no harm will be done?

Perhaps part of the difficulty lies in what is meant by "knowing". While one may memorize the rules and standard procedures, determining the right thing involves a complex, multi-level integration of what one knows (consciously or unconsciously) about the patient, the family, the physician, the hospital, the illness and treatment, and of course, one's self. The wisdom to know what to do requires more than data (facts), information (the meaning assigned to facts), or even knowledge (the synthesis of information) (Slawson, Shaughnessy, & Bennett, 1994). Wisdom, according to these authors, is "the appropriate application of knowledge to a particular situation [including] intuition gained from experience" (p.506). Further complicating the questions may be concerns such as a lack of agreement on the "facts" and "information" and the prevailing recognition of what constitutes knowledge.

Even when the facts of a situation are undisputed, they may be unknowable. Gerda Lerner (1978) describes her experience of her husband's illness with a high grade brain tumor:

> Carl undoubtedly "knew" before I told him and certainly many times refused to "know" after I told him. He was already deeply caught up in the process of dying and conscious knowledge was only a minor aspect of it. Just so it is with me now: the fact of his death, his absence, is incontrovertible. I "know" it in many different ways and with many different modes of perception. Yet, to this day, I still do not "know" it the way I know other facts. It shifts; it wavers -- sometimes it is as true as a rock; sometimes it is as true as a bad dream. I imagine it must be that way

for the dying until that final stage when they really "know" -- then they let go. (p.145)

Knowing so is more than thinking so.

Knowing is more than an intellectual experience, according to Sarah, another of the study participants. Her understanding of the `right thing to do' is based partly on past experience, partly on intuition, and partly on how she feels at a body level (visceral resonance?). She describes knowing at a "heart level":

> *...my instinctive response when you ask me `how do you know it's right' is that it has to feel right at a heart level. There [are] all kinds of intelligence that go into this with the information gathering and the assessment of that information and the decisions around all that data and that's all intellectual stuff, but it also has to feel right. I don't know how you define that, I don't think you can, but you have behind you the sort of a back up of the experience you've had with dealing with these people before and so you have that kind of comfort with having dealt with similar situations previously. But that's only part of it. It feels right, it fits right, and I guess the other piece of that is that you feel the person to whom you are giving that advice or recommendation is okay with it too. And it isn't right until you've clarified that. And it's got to be clarified by sensing out how that person feels.* (p.17)

Sarah shows, in this passage, the complexity of knowing the right thing to do. She also describes slowing down to "gather up ...the story," not jumping to conclusions or making

decisions simply because it would be expedient or because she "knows how". She engages in some "information gathering" that includes "intellectual stuff" (facts, data) within the context of both her own experience (having dealt with similar situations previously) and the experience of the patient (clarified by sensing out how that person feels). She is "backed up" by her experience, but "it has to feel right at a heart level" before Sarah knows it is the right thing to do. It is more than feeling, more than Sarah's own experience, more than the patient's unique experience, and more than the facts of the situation. Lynn echoes this notion when she describes knowing something in her "heart of hearts".

Philosophers have struggled for millenia to understand the nature of knowledge and the relationship between the knower and what is known (Hammond, Howarth, & Keat, 1991). What constitutes "knowledge," for an individual (or for the larger community, for that matter), depends on a complex blending of one's culture, gender, age, and experience. As Smith (1992) articulates, "knowing is a holistic and integrative process of making sense out of ourselves in our world" (p.2). For the last few hundred years, however, only that which could be empirically validated was considered worthy of inclusion in the broad category of "Knowledge" (Dzurec, 1989). The pervasive hold of logical positivism as the exclusive approach to knowledge development, and its attendant implication that one could, indeed, know with absolute certainty, may be traced in part to the work of Descartes. Hammond et al. (1991) note Husserl's "strong rejection" of Descartes' realist belief in "an external world, whose nature and existence are independent of one's knowledge of, or beliefs about, it" (p.17); in other words, a world independent of

one's lived experience. Within the philosophy of logical positivism, any knowledge or understanding of a phenomena that could not be measured or quantified could thus be dismissed as "unreal". Dzurec (1989) argues that human science researchers, nursing included, have remained anchored to the limited approaches of logical positivism as the exclusive path to knowledge development. She states: "It is probably accurate to say that most researchers did not recognise that they were using logical positivist techniques; they believed that they were using *scientific* techniques" (p.73). Wolfer (1993) elaborates by noting that earlier "constraint[s] of trying to force all problems into a positivistic straight-jacket" (p.141) have given way to an "evolving understanding" that "fundamentally different problems require very different types of methods" (p.141).

In nursing, the belief that one may ultimately "know" with the certainty implied by logical positivism, has led to what Benner (1984) refers to as a "template" approach to practice. Models have replaced context, she argues, and we have moved toward a mechanistic perspective within which everything (human beings included) can be considered machine-like, orderly, predictable, observable, and measurable. Benner states, "knowledge [thus] comes to be viewed as a product to be utilized, and the role of the clinician in developing knowledge is overlooked" (p.7). Benner suggests that knowledge is highly contextual and "person-dependent"; when I integrate what I have learned from *this* patient into my practice, s/he becomes part of who I am and what I know. The particularity of each person in the encounter, if each is afforded the opportunity for authenticity, precludes certainty.

All knowing is personal knowing.

Carper (1978) was among the first to employ a scholarly approach to the concept of knowing in nursing. She included in her description of the various ways of knowing: (1) empirics (nursing science), (2) esthetics (nursing art), (3) ethics (moral knowledge), and (4) personal knowledge. Smith (1992) postulates that fundamentally, all knowing is personal knowing. "Knowing is the weaving of threads of conceptions, perceptions, remembrances, and reflections into a fabric of meaning." Each weaver is unique and "the patterns and hues of each fabric are distinctive" (p.2). Gadow (1990), in response to Moch's (1990) exploration of the concept of personal knowing, writes: "The startling feature of personal knowing... is how thoroughly it permeates every human endeavour (even science) and how ancient a form of knowing it is" (p.167).

As nurses, as individuals with the knowledge of how to nurse and how to be a nurse, is the concept of doing the right (ethical) thing tied to who we are and therefore what we know? As women or men, sons or daughters, mothers or fathers, doing the right thing will thus arise from 'personal' knowing; unique to the individual but recognizable to others with similar pasts, backgrounds, and cultures. Knowing the 'right' or 'wrong' action will be connected to the particularity of the people involved in the decision making. Furthermore, knowing the right thing to do, whether one is patient or nurse, cannot be understood outside of the context; nor can it be predetermined with "certainty".

Smith (1992) asserts that "an ethical dilemma is the felt incongruence between a situation and our values. These values arise from an individual's explicit and tacit personal knowing" (p.3). She maintains that "the judgments we make about right actions are

personal... . Knowing right action comes from an experienced correspondence of choice with the authentic self" (p.3). The presumption within this statement is that we are free to make choices. What might this mean for nurses historically situated "in between" patients and physicians? Furthermore, when considering personal judgments about right actions, must we assume that we are able to recognise an "authentic self" among the many aspects of our "selves". How do we recognise authenticity? Would it manifest as a sense of harmony, or a lack of dissonance with the choices made?

Lynn has no difficulty extrapolating from her experience as a mother. She describes caring for a woman grieving for her child: "I felt just so badly for her, because I know how I would feel if it had been my daughter" (p.7,L.22). Later, she recalls chastising a resident for his apparent lack of concern for a gravely ill 18 year old boy being closely attended by his mother:

> *...he said to me "well, what do you want me to do? Nothing can be done. If he dies, he dies". And I said, "I'm sorry but that is an inappropriate response. This young man is 18 years old and I certainly hope you have not said that kind of thing in front of his mother". And of course he went "oh, I would never say it in front of his mother" and I said "well you said it at the front desk and you said it in front of all of us... (p.9, L20-25)*

After the tape recorder had been turned off, I asked Lynn if her experience as a mother made a difference in her work. She said that it did. "I love being a mother - it gives me insight in reading people, knowing where their strengths and weaknesses lie and why. I know who to assign to a difficult family and who I can't. I'll bring them in and put them

with a family. It isn't always necessarily me".

Lynn does not attempt to transfer her personal understanding to those around her; she recognises that what she knows and believes may be unique and she professes to being uncomfortable with making crucial decisions for others. She would rather "go in... talk to [patients] about the situation... educate them ...[and] give them their choice" (p.5,L.40,41). She notes that she cannot know with any certainty what her own wishes would be if she ever "got cancer," regarding a DNR request, or even regarding treatment (leading to her ambivalence about living wills). "I'm in no position to do that because I'm healthy and I'm not sick" (p.5,L.7).

Helen believes that her age ("the fact that I'm older") and her experience (having "done a lot of things and [having] been in a lot of different situations") allow for patients "to open up and talk about what it's been like" (p.7,L.37-38). She recalls caring for a seventy year old woman with advanced bowel cancer who had been admitted for palliative care:

> *...and I'm putting some lotion on her legs from the Body Shop and we were chit-chatting about the Body Shop and the nice lotions and then she suddenly comes out with "well," she said, "I'll enjoy this now because I don't have much longer to live." She said, "Do you think about what's going to be after you die? Do you think there's a God?" And I'm on my knees on the floor putting this lotion on her leg...* (p.7,L.8-13)

Helen responds by listening as the woman "open[s] up [to] talk about life and death... her children, her family...". Helen adds, "She was very much more relaxed after we talked, so I

felt good about that."

Personal knowledge, Carper (1979) concludes, relates to the ability of a nurse to transform an encounter with a patient into that of "I-Thou [that is] unmediated by conceptual categories or particulars abstracted from complex organic wholes" (p.18). Gadow (1990) echoes this notion when she states:

> Personal knowing is the opposite of generality. It cannot be expressed in general terms, but that is no impediment to its expression. The poets understand this, as do we all when we realize that before--and after--objectivity, personal knowing is the way each of us understands our particularity, and in the expression of that, each of us is poet. (p.170)

Knowing makes us vulnerable.

What does knowing something mean for cancer patients and the nurses who care for them? Is it easier to stand by patients who `know', people who have `accepted' the soon-ness of death? Knowing does not always mean accepting. Knowing can leave us exposed, vulnerable to the chaos of intense emotion; grief, rage, sadness. Newly diagnosed with prostate cancer, Broyard (1992) remarks: "When your life is threatened, you can turn toward this knowledge or away from it" (p.3). For Solzhenitsyn's character, Vadim, having cancer meant learning to cope with "living with the panther of death crouched beside him in the same hospital bed... living next to it like a neighbour" (p.249).

It is tempting to follow the path that seems to be the least distressing to both patient and care-giver; to ignore the crouching panther. Gerda Lerner (1978) relates the benefits of pretending that her husband was not dying of a brain tumor: while it seemed

senseless to build a wheelchair ramp at a time when Carl's condition was rapidly deteriorating, they forged ahead with enthusiasm. Gerda explains: "Strangely, we each of us knew the absurdity of our actions and deliberately continued to act "as if," because that seemed to be the only way we knew to deal with our reality" (p.146).

Marie tells of a patient who has taught her the value of acting "as if"; of *pretending* as a way of coping. Still, the "knowing" is there, and Marie can recognise through subtle clues when pretending has become too difficult:

> *...day by day I can have nice visits with her but probably once a week, because she comes in often, once a week I just don't pretend. I just sit there and we just don't pretend.*

Lerner (1978) wrote in her diary five month's before her husband's death:

> `Does he know?' [friends] ask. Yes, he knows. And then what? Knowledge is an ice-cold coin. You hold it in your hand and it chills you to the bone. It does not buy you the warmth of a drink, it does not offer you the breadth of a bed. No dream space. It's a skeletal certainty, which you might as well ignore. (p.194)

Yet for Ivan Ilych (1886), in Tolstoy's classic tale, the unrelenting pretending of his doctors, his family, and his friends becomes "torture":

> What tormented Ivan Ilych the most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result. ...their not wishing to admit what they all knew

> and what he knew, but wanting to lie to him concerning his terrible condition, ...and forcing him to participate in that lie. (p.137)

This deception leads Ivan Ilych to consent to treatment; part of the subterfuge that shrouds his final days. Dreading abandonment, he accepts the "familiar, sickly, hopeless taste" of more medicine. In the century since this story was written, have we moved closer or farther away from those who are dying? What role has technology or research played in "pretending" that death is not with us?

Do we, as nurses, facilitate the lie; "sorcerer's apprentices," as Tisdale (1986) muses? Or do we, in the hidden world of nursing, invite a knowing that includes the possibility of dying? "You need to know. There are so many things you need to put together [when] you know you are going to die," Helen states (p15, L31). Lerner (1978) acknowledges her mistake in not telling her husband his prognosis: "I should have told him... If he did not want to believe it, as he probably did not, he would have found a way to disregard it" (p.57). She adds,

> the terminal patient has no time for subterfuge and denial. If he does not want to hear the truth, he will shut it out. But if he does want to hear it, who are we to keep it from him? It is his death, not ours. Every [person] has the right to his or her own death (p.58).

Sarah (p.19, 20) tells the story of a family in which the husband was ill and the wife did not want him to "know" what was happening.

> *...[but] what eventually happens when you get to know a family like that is that you realize that it isn't the <u>patient</u> who doesn't need to know...it is the*

> *[spouse] who's needs you really are addressing, and [they are] trying to shelter [themselves] from the gravity of the situation, whereas the patient knows exactly what is going on. ...[I got her] talking more, [asking] a bunch of questions [to] get more information out into the open. ... [Y]ou get the conversation [to] open a little bit more. ...[What is also needed is] respect for each of those individuals, they needed to be in [their] respective space[s], and you honour that. And the next piece is to ...honour the love they obviously have for each other and whatever strength of relationship they have and see if you can facilitate their coming together with that and be more open with each other.*

Marie states that it is often nurses who notice "clues" that a family is ready to "know what's happening," through spending many hours with a patient and family and getting to know them. "It's those little comments like `well, what do you think about dad going here for Christmas'...that give you the opportunity" to help them let go of the pretending; to do the things they have so little time for. Marie acknowledges that she also needs to pretend sometimes; to ignore the idea for a little while longer "that maybe this last ditch effort that we are trying might not work" (p.11,L31-32).

In the end, we will be as vulnerable to knowing as we allow ourselves to be. As Gerda Lerner (1978) expresses: "He really knows. So, perhaps, after all these years what we can do for each other is to spare each other from words. ...Somehow, our hands have always known everything there is to know. Thank you for silence" (p.195).

Knowing without certainty: Living the question.

The caution, the yellow flag in one's experience of personal knowing is articulated by Kurtz, cited in Munhall (1993): "Knowledge screens the sound the third ear hears, so we hear only what we know" (p.128). If this is so, personal knowing may not be sufficient for the ethical understanding of the experience of another. It is essential that we endeavour to extend that which we know, expand our capacity for knowing; to strive for knowledge that eschews certainty or premature resolution of the issues. Munhall describes "unknowing" as a way of avoiding closure; as a way of remaining open to the other; a condition of openness. She asks that we "proceed with an air of mystery and an attitude open to alternative interpretations" (p.127). Does an experience of dissonance, a sense that something is not quite right, lead to unknowing? Is unknowing another way of describing Bergum's (1991) notion of "living the question"?

> ...to `live' the questions... means keeping up the search for understanding, constantly questioning what is taken as secure, accepting the fact that there is still more to learn, and searching for another view of the complex reality of living, which may open further depths of questioning and understanding (p.69).

Munhall (1993) talks about the challenge of "practicing in a wide-awake manner" (p.126). Perhaps `curiosity' is a term that should be included in this discussion of "unknowing". Entering the room, the space, of a patient without a pre-conception of what will happen or what should happen does not imply that a nurse will leave her knowledge of herself or her experience and skills as a nurse at the doorway. It does imply that it is the relationship

between nurse and patient that is at the "core" of ethical practice. What occurs within these relationships must move beyond principles to embrace the particulars of the people involved. The highest principles are limited in their capacity to guide specific practice situations. One cannot begin to "know" in an ethical way, outside of the relationship. For Lynn, certainty is tempered by context; the particularity of a situation may be as important as regulations. "I think we need to have rules and I think that we need to come up with solutions... brainstorm[ing where] everybody sits down and thinks" (p.3,L.36).

Different nurses "know" different things in the same situation, illustrating the notion that there is rarely an objective or "truthful" interpretation for an unfolding clinical story. Marie describes caring for an aunt who was dying. She had asked Marie to ensure that her death be free of pain, and at this point was lying semi-conscious in her hospital bed. Marie recalls that her aunt's nurse was quite concerned about the drowsiness, stating "well, I think she's had too much [medication], she's too sleepy, I think we should stimulate her." Another nurse, however, encouraged more analgesics, noting that "she grimaces when you touch her." There were three nurses in this story: a nurse/family member, a nurse concerned about over-sedation, and a nurse concerned about the level of pain. Each nurse viewed the situation from her own personal "Gestalt," with particular aspects in the foreground and background for each.

This story is neither completely "relativistic" with one nurse's opinion as valid as the other's, nor is it completely objective. An objective knowing may be found in the ever-growing body of knowledge about pain control that is available and essential for cancer nurses incorporating, in part, data about effective drug doses, side effects, and alternative

methods. Any facts about pain control are inadequate, however, when considered in isolation of the patient's wishes. Marie's aunt had made her wishes known: to die without pain. Marie knew this, but reported that she felt unable to speak "as a nurse," and was "too exhausted" to speak up as a niece, describing the uncertainty experienced by many cancer nurses caring for family members. The two attending nurses had to balance their knowledge of pain control, the patient, the family, the physicians involved, and their work-load for their shift in order to determine what was right (or best, or better, or the least harmful). Included in this complex equation was each nurse's personal values and feelings about end of life issues.

The ethical resolution to the problem of choosing between giving more or less medication to Marie's aunt had to lie with the patient's expressed wishes. While increasing the morphine meant risking increased sedation and respiratory depression, *not* increasing it, or, as one of the nurses suggested, decreasing it, would have meant ignoring the patient's wishes; keeping her in the general narrative rather than the particular.

There is a place, a role, for certainty, and there is a time when certainty can be harmful or even destructive. Understanding the difference is essential to ethical practice. The experience of "unknowing," of "living the question," has been described differently by nursing scholars and researchers who understand its centrality:

1) Benner's Expert: (1984) "The expert performer no longer relies on an analytic principle (rule, guideline, maxim) to connect her or his understanding of the situation to an appropriate action" (p.31). Each situation is approached as unique, yet experience with similar situations is crucial.

2) Watson's "Actual Caring Occasion": (1988) "The moment of coming together in a caring occasion presents the two persons with the opportunity to decide how to be in the relationship - what to do with the moment" (p.59).

3) Van Manen's notion of "Tact": (1991) "We speak of tact as... knowing what to do, an improvisational skill and grace in dealing with others" (p.125). He explains that "in a sense, tact is less a form of knowledge than it is a way of acting" (p.127).

4) Gadow's "Existential Advocacy": (1980) Nurses may engage in "participating with the patient in determining the personal meaning which the experience of illness, suffering, or dying is to have for that individual" (p.97). "Moreover, the nurse offers a necessary alternative perspective which complements and completes the partial perspective of the patient..." (p.98). Gadow (1994) adds that discourse ethics is not a normative framework: "Rather than describing a system of values, it describes a condition - namely, relationship - for the creation of values. The single value that is presupposed is non-coercion... Ambiguity is the space where moral agency exists, where imagination operates, and where relational narratives about... health care can be created" (p.11).

5) Bergum's notion of "Nurturance": For Bergum (1994), ethical decision making requires that both patient and professional share in the journey being undertaken: "Participation at this level involves subjectivity and objectivity, and involves risk in responding authentically to one another. A nurturing relation does not necessarily have a specific outcome that is sought (e.g. care or cure), nor can an outcome be predicted. ...With nurturance, cure is only one of the many ways healing can occur". (p.78)

On Timing

Dying is cruel, either by being too fast or too slow...

Lerner (1978, p.263).

Brock (1993) contends that illness, the timing of it... now instead of sometime in the future, can seem irrational to us. How can this be happening now? Even for the very elderly, there is no rational `time' for illness. Solzhenitsyn (1969) writes:

> Since men are mortal, Rusanov had always known that one day he too would have to hand over the keys to his office - but `one day', not this very moment. He was not frightened of dying `one day', he was frightened of dying now. What will it be like? What will happen afterward? How will life go on without me?" (p.255).

To know that one has cancer is to lose whatever has been taken for granted about one's experience of time. "What was it like to be told that I had cancer?," asks Frank (1991). "The future disappeared. Loved ones became faces I would never see again" (p.27). "He became like a moving body approaching the speed of light," writes Solzhenitsyn (1969). "His years were being compressed into weeks, his days into minutes" (p.249). To articulate the anger and fear often connected to a diagnosis of cancer, Solzhenitsyn adds: "This damn illness had cut right across his life, mowing him down at the crucial moment" (p.246). Would any moment not be crucial?

Yet Frank (1991), cured, or at least in remission from his cancer, describes his diagnosis as a "dangerous opportunity" for exploring how to live his life to the fullest. Even during treatment he noted that "life [had not] stopped during cancer. It had only

intensified. If the months [of treatment] seemed like a lifetime, it was only because during this time everything counted. I could not afford to let anything slip by unobserved and unfelt" (p.132). Life did not stop, but Frank's experience of time became altered, slowing down, speeding up; gradually returning to "its normal pace". When everything counts, time becomes very precious; something to be attended to, honoured.

Pacing allows long distance runners to `go the distance'. What of the pace of illness? Weston (1979) writes:

> Truly our environment pulses with rhythms. As the sun rises and sets, all life on earth ebbs and flows with a constancy that matches the movements of the tides. Our cohabitants on earth, whether flora or fauna, march to their own drummers. And most of all, man in his ultimate complexity is a rhythmic creature (p.130).

Timing, rhythm, and knowing.

Through stories of caring for in-patients on a recent shift, Helen illustrates the close connection between knowing the right thing to do and knowing when to do it. She is attuned to the rhythm of her patients and their families; each with their own experience of time and timing. Gently encouraging a visiting daughter-in-law to sit for a while and hold her mother-in-law's hand, Helen takes the time to talk to her about how "she really isn't any different, but generally, gradually, her condition is worsening." An unexpected admission arrives "barely responding" and requiring Helen to "do everything ten minutes ago"; "you have to start the IV, start the oxygen, do a chest x-ray, do an ECG and bloodwork and get him downstairs to ultrasound... and in the middle of all this you have

to support the family..." (p.14,L23-26). Helen encourages his wife to stay the night, just in case. There is another patient...

> *I've got somebody now that I'm kind of working on. She's elderly and doesn't [complain of] pain, and [I don't think she has pain], but to my mind she's not totally comfortable. I had her on nights a couple of nights last week and at no time did I catch her with her eyes closed, and she was, you know, kind of confused but her mind was going obviously very fast. I kept telling the people on day shift and evenings. We did get some night sedation, at least, for her so she's having better nights. So that was good, [but] I still feel that she should be getting a little bit more of something, even if it's only 5 mg of Morphine just to make her feel more comfortable. It's not so much pain [as it is] comfort.* (p.12,L.10-30)

Helen notices over night shifts followed by day shifts that this elderly woman seems to be suffering something other than pain - a lack of comfort. Helen, acting on what she has come to know, "works" on this situation over time.

Timing and particularity.

In another care situation, Helen describes working with Bill (a pseudonym)...

> *...The doctor came in and told him that the tumor was kind of wrapped around his [spinal] cord and that maybe they could offer a bit of palliative RT [and] they would get a surgeon in, but that he didn't think that there was anything that could be done. [His] family was not in. I heard some of this conversation and then I heard him phone his family in*

(his home town). I spent a bit of time with him talking about what the physician had told him. He did most of the talking ...[and] said "well...what can we do - that's the way it is" - he's not an old man, he's quite a young man - he says "I guess we'll try the RT ... I don't really think I need any more surgery." [I don't know] whether he has any idea of how this is going to be - like a paraplegic - I don't think that has quite sunk in yet because of course every little part of the treatment kind of gives you a bit of hope [and] that was the way we left it. I think that was as far as he could go today ... he'd be trying the RT and if it didn't work then we'd have to think again what we'd do. Right now, the decision was that he would be simulated [treatment planned], have a little bit more RT and see if there was any improvement. And I think that's the way it's done - gradually - you know, the realization will set in if things don't go well and that will be soon enough then to handle that. (p.13,L.1-20)

The patient, Bill, is not ready at this point to discuss the possibility of paraplegia and what this could mean for him. Nor does he mention the possibility of dying as his tumor continues to grow. Helen recognises that his life is unfolding; as a story not yet written. She has seen many patients "like" him, but as she tells her version of his story, she mentions the details that point to his particularity - his age, his home town. Details about Bill's life that can seem slightly out of place in the `objective' world of science and treatment. Sarah echoes the notion of particularity:

The way to help people accommodate to their disease, accommodate to

> *their life situation as a result of the disease" means "lay[ing] the cards on the table... you can do it by laying those cards down very gently...and the order...and the rate at which you lay them down might be different according to each individual, but to me that is how... you can establish rapport with people. That is how you help them through* (p.19,L18-26).

Helping people through requires an understanding of the differences between people, knowing details about who they are, a sense of their experience of time.

Significantly, Helen has not labelled Bill's experience; for example, there is no mention of `denial', nothing said to reduce him to the category of "Bill as such" (Gadow, 1992). He retains, in Helen's story, his individuality. Arthur Frank (1991), having lived through an experience of having cancer, explains how important this is:

> Care begins when differences are recognised. There is no `right thing to say to a cancer patient' because the `cancer patient' as a generic entity does not exist. There are only persons who are different to start with, having different experiences according to the contingencies of their diseases. The common diagnostic categories into which medicine places its patients are relevant to disease, not to illness. They are useful for treatment, but they only get in the way of care. (p.45)

What is it like for Helen as she works with Bill? What choices exist for her in this relationship as Bill struggles with his decisions? She could consider the ethical possibilities afforded by principles such as autonomy (acknowledging Bill's `right' to make his own choices) or beneficence (searching for what might be `good' for Bill). Instead, she listens

to him sort out his thoughts, his life, recognising that he has gone "as far as he could go today." Helen receives Bill's point of view; within the finite number of minutes available in this shift, she has decided to spend some of them in this manner. People usually know when they are dying. Bill will probably `know'. If not today, then "soon enough". As Helen says: "the realization will set in if things don't do well and that will be soon enough" (p.13,L.18-20).

There is a cadence to our lives, similar to that of other human beings, yet as unique as personality. Weston (1979) cites research involving isolation of individuals from all external time cues as evidence for a distinctive experience of time. Although most people adopted a circadian rhythm of twenty-five hours, the range extended from sixteen hours to thirty-four hour days. Whether their days became long or short, almost all participants reported a "sense of contentment, well-being, and a feeling of harmony" (p.31) when allowed to find their natural rhythms. Moore (1992) has observed that many ancient physicians were also musicians. He writes:

> They were concerned with the rhythms, tonalities, discords, and concords of the body and the soul. They taught that a doctor, when treating any kind of malady, must know something of the patient's music. What is the tempo of this disease? With what life elements is it in counterpoint? What is the nature of the dissonance that the patient feels as pain and discomfort? (p.170)

What can an exploration of time and rhythm teach us about illness, the experience of illness, about nursing and ethical nursing care? Marie talks about "clues" for knowing

whether a patient is ready and willing to "get down to the real shit" - talking about dying, about what the cancer has meant to them.

> *I sometimes [become] aware of the way I'm talking to them. I'm lecturing at them and I know I am. My voice is different, everything is different. So, [you] throw away those teaching materials, sit down, put your shoulder against theirs... just sitting there... sometimes I don't even say anything [but] I think about him and what he's doing... and we just start to talk like we're having a cup of tea and we get down to the real shit. "I care about how scary this is" is much more important than "well, we can give you another drug" and ...eventually if you sit down and you just kind of kick back you hear a little "I'm so scared"* (p.10,L.20-39)

Over time, several visits, Marie learns the patterns and rhythms of Julia, a nurse who, through the diagnosis and treatment of her cancer, has become Marie's patient and friend:

> *[Instead of] bringing friends or breezing in and breezing out, she'll come alone and say "I want to talk to you about something," and it will be some scientific thing...more research...and what about this or this...and we cover that for about 10 minutes and then we might spend a half hour talking. I might say "how are your kids" knowing full well that her daughter is away at University and should come home. We talk and she'll say "I don't think they're ready," and I'll say "you know that they know," and she'll say "ya, I guess". Then this week, she told me that her daughter is coming home. She needs to have [her daughter] there because she's not*

going to have much time. (p.11,L.7-27)

Timing and synchronicity.

Can we be tempted to move someone too quickly along a path `for their own good'? How easy is it to interfere... to add in technology, more chemo, another protocol? How do we recognise the differences between Bill's path, his pace, and Helen's? What about the differences between Bill's pace and rhythm and that of the cancer care `system'? Helen demonstrates an understanding of Bill's rhythm. She does not compel him to `know' too soon.

How did Bill first learn of his cancer? Did he know his body well enough to feel when something wasn't quite right? Or did someone else know first; a doctor palpating a suspicious thickening, a radiologist noting a shadow on a routine x-ray? Somehow, somewhere, Bill's path was altered, a detour taken. Cancer changed the course of his life. Time "tapped [him] on the shoulder" (Broyard, 1992, p.3). The rhythms of Bill's existence were altered, coaxed into synchronicity with the pace of treatment. Waiting, waiting for tests, results of tests, to see the doctor... moving too fast, too slowly... Dying too soon, holding on too long... an hour until my next pain pill...

Lerner (1978) describes the experience of her husband's admission to a large institution:

> This hospital, a huge, anonymous organism, quickly absorbed us in its rhythms, and turned us into minor actors on its crowded stage. ...We became so much a part of it that a new patient or the departure of an old one, the vacation of an orderly or the weekend absence of certain nurses

were "events" in our lives. (p.72)

Marie recalls a patient she had cared for several years ago, describing one of her first experiences of speeding up a situation that "was all too slow". The patient had leukemia and severe bone pain, and had been admitted "in the very end stages" of her illness. "She had gone through so much and she depended on us for so much ...and she said `please just don't let me have pain... they promised me I wouldn't have pain, and Marie, I'm having so much pain'" (p.4,5). Marie immediately contacted the physician and insisted on an order to "titrate up her morphine" until it was effective. She notes that she bypassed proper channels, deciding instead that she would "take care of this now, myself, I am there for this person now." The patient died within 24 hours, without pain. Marie doubts that this would constitute euthanasia, even if the morphine hastened her patient's death by a few hours. Helen concurs:

> *...I'm thinking of...somebody comes to mind right away...his wife was a nurse and I can remember saying to her that, you know, his condition was deteriorating and that this might be the last time I'd give this and did she still want me to give it and she did. She said yes.* (p.3, L.33-36)

When asked how she would have handled it if his wife had said no, Helen replied:

> *I would have just waited... sometimes you might delay it because there are more people on their way in to see the patient and so on. But... I don't have any problem with giving it until death occurs because, you know, I just feel that once all hope is gone and there is no quality of life, then the kindest thing we can do is to ease them into death.* (p.3,L.38-44)

Weston writes that knowing our rhythms, embracing them, respecting "the ticking of our internal clock" will lead to a sense of harmony, equilibrium, and health. From the steady beat of our mother's heart as we first experience the world to the rhythms expressed in poetry, dance, music, the pulse and meter of our lives compels attention and expression. In the ancient Greek world of Plato and Aristotle, the connection between music and life was recognised and honoured. Grout (1960) notes that they eschewed all music that was not harmonious and pleasing in rhythm and form, thereby promoting courage and temperance:

> The word *music* had a much wider meaning to the Greeks than it has to us. It was an adjectival form of *muse* - in classical mythology any one of the nine sister goddesses who presided over certain arts and sciences. ... In the teachings of Pythagoras and his followers... the system of musical sounds and rhythms, being ordered by numbers, was conceived as exemplifying the harmony of the cosmos and corresponding to it. (p.7)

The musical relationship between lived body and spirit has been understood and celebrated by composers and musicians throughout the millennia. Grout (1960) writes that music is "ordered sound and rhythm" for communicating internal "impressions, thoughts and feelings". By way of example he notes: "Schopenhauer believed that music was the very image and incarnation of the innermost reality of the world, the immediate expression of the universal feelings and impulsions of life in concrete, definite form" (p.494). Griffiths (1986) is more succinct, describing music as "the art of time". We may learn from those for whom the experience of time engenders music or poetry or dance.

Sarah describes a lack of synchronicity with a patient during an earlier stage of her career, which lead to an occasion where she "got it wrong"; where her `nature', her rhythm, superseded that of the patient:

> *My nature is to be very direct... I can be fairly bustling in certain situations where I think people can be, sort of, pushed along a little bit... and obviously that wasn't appropriate in that home. I made them angry.* (p.5,L.46-51; p.6,L.4)

Citing Bollnow's notion that patience is "a virtue which reconciles human beings and time" (p.10), Will (1993) notes that haste is the opposite of patience. She adds, "with haste, one attempts to leap into the future, to bypass some aspect of the present" (p.10).

Zerwekh (1990), in her study of expert public health nurses, found that timing was integral to caring for patients and families. She noted that the nurse would:

> ...[match] her speed in pushing for change with that of the client's movement toward change. Another nurse elaborates that if the nurse is continually frustrated at client speed, she needs to step back and evaluate what is realistic. ...Supporting dimensions of Timing included detecting the right time, persisting, and "futuring." (p.88)

Sarah describes her understanding and respect for the need to match her own rhythm with that of the patient:

> *You have to take your time - something I'm not always good at. And by that I mean you have to gather up as much of the story from the person or the family member or both, as you possibly can. You know there are some situations that are*

going to be very classic ones, [where it would be] very easy to just go jumping ahead and make decisions [when] you know how to make the decision. I have to constantly remind myself to slow down a little bit - have [I] got all the facts - and then when you have all the facts and you're going to make a decision or you're going to be a participant in helping with some decision making. (p.17,L.24-32)

Later, Sarah describes coaching a man being treated as an out-patient (I'll call him Mr. MacLeod) who is reluctant to take a narcotic analgesic for fear of addiction. (p.18)

...it became apparent that morphine would probably be the next step but it took a couple of weeks to go with the morphine and I realized that. I would make the suggestion to him and then I would [add] "you're not very happy with that, are you?," just to see what would come back from him...and back from him came these concerns about "well, that's pretty strong stuff, isn't it? I'm not ready for that yet, am I?" (p.18,L.21-28)

Sarah refrains from delivering a sterile lecture about pain control methods. Instead, she respects his rhythm, his wish to maintain control of and in his life. But Sarah also does more; she engages in the "futuring" described by Zerwekh (1990). In Benner's (1989) words she provides him with "the imagination required to take the next step and move into the future" (p.65). She tailors the information to Mr. MacLeod's particularity, his "take charge" manner. Sarah describes a process of "normalizing" the taking of morphine by linking it to the opioid component of his Percocet® and emphasizing the long-acting feature of the morphine compound. Mr. MacLeod is not labelled as `irrational' and neither are his decisions. As Sarah notes, "...this takes time and a great deal of sensitivity to where

that person is at a given time and dispelling the myths, you know" (p18,L.44-45).

Sarah engages in a dance with this man, throughout which she variously leads or follows according to the cues he provides. She knows she could help him, but she also knows that it is difficult for him to "hand over the reigns of control" and that he imagines himself unchanged in spite of advanced cancer, shortness of breath, and esophagitis. "I've followed him for about six weeks now, and he'll open the door a little bit and let you in and then shut it again..." (p.12,L.9-11). Sarah searches for "safe" ways to help and has begun to make headway through concrete decisions regarding pain medications.

The next passage shows Sarah's understanding of Mr. MacLeod's experience of time, although she does not articulate her understanding as such. Their beginning rapport was dissolved when a suggestion was made by a physician that Mr. MacLeod might benefit from a psychology consultation, a suggestion that Sarah supported.

> *...I was in the room with [him] alone, and the kind of rapport that I felt I had begun to establish on the previous visit... was suddenly all gone. And you... sort of take a quick breath and you think, oh dear, now what have I done? And then just as quickly, I... put it together. Where he was allowing me in was more concrete...* (p.12,L.28-35)

Mr. MacLeod is very present oriented and will avoid discussion of past or future (therefore, no psychologist). Sarah gradually, over the next six weeks, regains his trust through focusing on "concrete things" and specific symptoms, letting him know that she "simply want[s] to know his story at the time". In spite of her frustration, her wish to "get in and establish this rapport," to "get in there a little closer and a little faster in order to be

of more benefit," Sarah has slowed her tempo to match Mr. MacLeod's. She respects his need to remain in the present, to maintain control. "[I'll] stay where he wants [me] to stay ...[I'll] give him that kind of respect" (p.13,L.29-30).

Marie expresses her understanding of the rhythms of working with people who have cancer: "you personally become very aware that you are here for such a short time and for just a brief moment [we] maybe have the opportunity to make a difference to somebody or to something. So take the moment" (p.15,L11-14).

On Relationships

Can we decide the right thing to do by simply imagining or projecting ourselves into the experience of another? Benhabib (1987) addresses the difficulty inherent in determining the ethical course of action by "taking the viewpoint of others". She cautions that one's own experience must not become a normative standard by which another's choice may be judged. What is `right' for you, she argues, may become confused with what would be `right' for me. Benhabib further asserts that Rawl's classic notion of objectivity, the use of a "veil of ignorance" for deciding right action, leads to the disappearance of the particularity of everyone involved, restricting each to the role of "generalized other". What is lost, then, is "all that belongs to [us] as embodied, affective, suffering creatures, [our] memory and history, [our] ties and relations to others... what we are left with is an empty mask that is everyone and no one" (p.89). From this nebulous position, details and context cease to matter; rules for standardizing conduct increase in importance. As Benhabib states, "differences are not denied; they become irrelevant" (p.89).

Gadow (1993) expresses concern about mistaking the generalized for the concrete, thus leading to the "disappearance" of either the patient or the caregiver in determining an ethical course of action. She examines and compares the various narratives, or social constructions, available to us for explaining why things are the way they are. For example, we may look, according to Gadow, to the general narratives derived from science and medicine to find the germination of the belief that knowing with certainty, outside of relationships, is possible. She argues, however, that

> [n]o general ethical narrative can establish for [an individual] access to their experience. Even a theory of caring becomes ideology when its author speaks not as a particular person but as if the theory were speaking, as if its words were more than true, more important, than the words a woman [or man] and caregiver say with each other in their situation together. (p.11)

If we postulate that `the right thing', or `the ethical thing' is to be found in relation, then we must explore what it is that facilitates or interferes with relationships between nurses and patients, or nurses and other staff members. What prevented Marie's experience in the initial story from becoming one of cynicism and detachment? In her story, Marie described a crucial debriefing session that allowed her to process what happened. Was this the difference? Was she able to re-write the narrative and thereby change the relationship and re-connect with the physician and with her colleagues? Helen recalls her initial experience in connecting with other staff members: "[A]s I think back... to my first grounding in people caring about people in terms of staff relationships; as students... if we felt that we couldn't do this, give this [final dose of pain medication], that the [nursing supervisor] was

willing to do it for us. I think that had a big impact on how I feel about it now, I mean I think it's the right thing to do" (p.3,L.25-30).

Helen states that communication difficulties with physicians will sometimes occur with "the ones who just come at night and do not have overwhelming experience in oncology". While most will "take our suggestions pretty well," conflicts can arise if they "will not go along with what we're suggesting" (p.11,L.9-14). When there is no possibility for seeing that the right thing can be realized because of an inability to connect with a particular physician, the physician may be bypassed. Attempts to establish or maintain a relationship with physicians who show a lack of respect for nursing input, or for the experience of the patients, will continue only insofar as the physician remains crucial to the care of a particular patient. "If it's a real problem," notes Helen, the nursing supervisor will be asked to contact either the staff physician on call or the patient's primary physician. She adds that there are some "on-call" physicians who will adapt and change over time as they learn the concepts central to oncology. "I think it does have a profound effect on them and I hope that it's going to be a good effect because I think that, you know, places like [this cancer hospital] need to spread the Gospel, as it were, about compassionate care and pain control, ...we have so much to teach about those kinds of things" (p.16,L.29-32).

When asked if she could recall a situation that felt "unresolved," Lynn recounted an experience with an "extremely angry" woman, the mother of a young woman at the "end stages" of her illness. Lynn recognised a complex combination of "legitimate reasons" (poor treatment at another hospital, delayed diagnosis and treatment), and an ongoing "grief process," in the mother's anger. In spite of the best efforts of the staff, complaints

were made to the hospital administration about the nursing care. Lynn felt "so badly for her," and noted that if the young woman had been her daughter, "I would have been just sick". She did not take the complaints personally, choosing instead to look "deeper" (p.7, L30-34):

> *...we can offer them psychological care and pastoral care and whatever else but they [can] refuse all of that. Sometimes you can go back again and eventually build up kind of a relationship with them and...other times there is no way. There was no way I could build up any kind of rapport with this woman and none of the nurses were able to either. She was just so devastated.*

In the end, Lynn chose to "just listen". The barriers to a relationship with this woman were too high. Perhaps Lynn intuitively permitted what Lerner (1978) describes as a necessary outlet for the expression of anger:

> What I did not know and could not then face was my anger, my rage, my sense of being robbed and cheated. [The health care system/staff] provided me with a focus for that anger, and fighting [them] was a way for me to release my feelings. ...The patient and family have to react somehow to the disaster that has struck them so unfairly and overwhelmingly (p.77).

Respect is not always reciprocated by patients, and Sarah notes that she does not always have a choice in working with demanding or difficult patients (this is true of most nurses). How does she cope with patients who frustrate her, maybe anger her, in spite of several attempts at establishing rapport?

> *I have had to... withdraw myself [and say], I'm going to go now but I'll be back... I do that when I recognise that I'm so frustrated that I have to go away and feed myself... nurture myself, get back my own energy and my own patience...* (p.15,L.22-29).

Sarah discusses anger expressed by patients toward her: "if you're going to be a survivor in... oncology nursing, you have to learn how to respond to that kind of emotion, angry emotion coming toward you, by realizing that you don't have to buy into [the] anger" (p.4,L.2-6). She describes a situation involving her own anger toward a patient and about maintaining a relationship in spite of his unpleasant behavior. Staff had shared their general dislike of this patient. Sarah recognised that "there [wasn't] any reciprocity there," but that "you aren't going to make any progress with a patient like this unless you do your utmost to [maintain a] relationship". It takes, she added, "wisdom to know when you've run out of energy, and get away" (p.11).

Lynn includes her relationship with her "self" among those she values, noting that "a healthy lifestyle is absolutely vital to working in a [cancer hospital]". She has learned to take care of herself through "all kinds of stress relievers" such as regular exercize and paying attention to her diet. In a recent (McKinnon, 1992) unpublished integrative review of seven phenomenological studies investigating ethical dilemmas, it was found that several studies included nurses' descriptions of physical complaints. Nurses reported feeling "drained," "exhausted," and "physically worn out". It would be interesting, in a future study, to correlate feelings of fatigue with the experience of powerlessness and frustration, to determine the effect of one on the other.

Helen states about relationships within the hospital:

On the inpatient units I would say that we really work as a team and physician, nurse, psychology - all the support services - housekeeping, dietary, I mean all of these people play a part and I... you know, when I see some of the compassionate care from the dietary ladies and the housekeeping people... I mean I could just fill up thinking about it because they're all... [so] good ...I mean it comes from the top, that kind of thing, so everybody is working together for a common good and I really believe that the patients benefit from that. (p.11,L.35-42)

Knowing when to push (and where and who and what).

Marie continues to question herself and her ability to put what she knows into practice. "I know I've come a long way [but] I think I learned the hard way... It is the worst thing in the world to go home... and at three o'clock in the morning you're saying "why didn't I keep on pushing...why didn't I do something... why didn't I...?" (p.6,L.4-7). Pushing implies moving something, or trying to move something or someone; a barrier or something heavy that must be moved out of the way, or started up once it has stalled.

In spite of knowing that "pushing" a physician, in certain situations, is the right thing to do, Marie describes sometimes feeling "scared that I'm going to cry". Most of the time she is able to overcome her fear of angering or upsetting a physician or another nurse, to seek a resolution acceptable to all. As an example of this, Marie recalls refusing to allow a potentially risky procedure to be performed on a patient. The attending physician "decided to yell... I kept walking towards him and he kept backing up and

yelling" (p.6,L.35) ..."I thought about it and worried all night and went back and I was so scared and so worried" (p.7,L.1). Marie met with the physician and discussed her concerns about "putting this lady in a tenuous situation" that they did not have "the resources to get her out of". "You needed to know that," she added. The physician responded that he was also "really worried about that". Their mutual resolution of the issue started a friendship that continues to this day. Marie chose to build a relationship with this physician, in the best interests of the patient, rather than perpetuate a conflict in which all would lose. She continues: "I'll play lots of games to get what I want for the patients but sometimes you have to be really forthright, no holds barred, and say `I don't like this'" (p.7,L.37-39).

Sarah (p.6,7) notes that one can be a "pushy advocate" for patients without cutting off communication with physicians. She explains that for her, advocating for patients also means knowing the doctors in their particularity; knowing when to `suggest' something, what to suggest, and how to suggest it with "diplomacy," avoiding "ruffled feathers". She describes being with patients, working with them, comprehending their pain... "You have an obligation to see... to push... [until] attention [is] paid to that issue." Sarah admits to being "angry that I can't have more impact on particular [doctors] to address the issue of pain... to [compel them to] care more, really."

Lynn recalls a situation where the resident had left a written order that the nurses were to be responsible for ensuring that a patient receive oxygen through a mask instead of through nasal prongs:

> *Her [oxygen] sats were much better and she was less anxious when she was on a mask, but no matter how much teaching he did [or how many]*

> *people would stay with her and how much we tried to get her to wear that, she was still so claustrophobic that she couldn't. She actually preferred to ...feel a little more anxious, which we might be able to relieve with ...some kind of sedative, and wear the nasal prongs. I was very angry when I saw that order... (p.5,L.27-33).*

Lynn applauds the changing times wherein patients "know their disease sometimes better than we do" and will "refuse to just take an authoritarian type of decision any longer. They want to be a part of that decision and that is right" (p.6, L6-10). Recounting a similar experience several years prior to the incident described above, Lynn recalled that she had been "reduced to tears" by a physician who insisted that a dying patient be forced to wear an oxygen mask. Lynn respected the patient's request for nasal prongs and continued to make the patient as comfortable as she could in spite of the physician's denouncement that "if [the patient] dies overnight it will be your fault." It may have been simpler for Lynn to give in and put the oxygen mask on the woman; people who are dying have little energy for protestations and will usually submit to pressure, however well intended. In the end, Lynn did what the patient wanted, rather than what the doctor had ordered. With time and experience, Lynn has become more secure in her resolve to follow the wishes of the patients. She is also comfortable with telling patients, or families if the patient is unresponsive, "that they have rights" and can refuse treatment.

Lynn states she tries to avoid causing "hard relationships" with physicians by informing patients about their rights in a manner that is "tactful". She both "knows" and is "known" by the physicians through having worked in various positions throughout the

hospital. This, she believes, is part of the reason that she might be listened to when other nurses might not. Lynn will do what she can to "smooth over troubled waters"; preventing or reducing conflict between patients, nurses, and physicians. Lynn wonders whether it is her age, her position, or her experience that empowers her. In order to maintain excellence in care, Lynn is willing to do whatever it takes; cut costs, expand services; she will "keep pushing" with her vision of care until "someone says `let's sit down and talk'".

Helen remembers the deaths of people she has cared for in the past in other hospitals, deaths that have "outraged" her, "haunted" her. She recalls her frustration with a physician who "did not believe" in the latest pain control methods, who discontinued MS Contin® on a patient who had been in good pain control and ordered an inadequate and inappropriate alternative (p.5). When asked whether she had recently felt "powerless" to see that the right thing was done for a patient, Helen states that "it is generally not my experience at [this hospital]". She does recall a time, however,

> *when we had a patient with, I believe, lung cancer and the resident on that particular night was not able to let nature take its course. I came to work - I was on day shift - and I had a student with me and... this lady was so ill they called us out of report. And so I went into the room and there's this physician struggling to take blood and blood gases, and ordering all kinds of medications now, now, now, now. And I have a problem with that sometimes. It happens so rarely, and it's usually just individuals when they're young and not able to let the patient go or not able to let them die comfortably. That particular time I did feel quite powerless because I*

> *came in on the situation... we weren't able to sort of delay calling the physician, you know, the physician was there and he was burrowing around for an artery. That I found very stressful. And he got his blood, and we gave her all kinds of medications and she died the following day. Her family was all there and in the end they called a halt to anything more for their mother.* (p.9.L.16-30)

Helen notes that she will usually deliberate with her nursing co-workers before determining the "right thing" to do for patients who are "palliative" and slowly deteriorating. The medication room on the unit is often the spot for "deep discussions" about "ethical things" such as when or even whether to call a doctor, according to Helen. "We'll talk to whoever is on [shift] with us... sort of go through all the signs and sort of think what's happened before and our knowledge of the family and what they would want..." (p.10,L.4-7). If the physician on call is known to be "very aggressive," Helen adds that "we may well drag our feet a bit".

Marie elaborates on her willingness to "play all sorts of games" in order to get what her patients want or need. She readily dismisses the "general knowledge" (the general narrative) about her health care colleagues and describes with confidence her ability to advance her patient's cause. "I don't want to hear a report that so and so is in a bad mood, or so and so doesn't have a good sense of humour, or... this is how you handle that doctor..." (p.8,L12-14). This information, presented as possible barriers to facilitating the right thing for her patients, is irrelevant to Marie. "I have some skills and some knowledge [and] ethically I should use those skills and knowledge..." in the best interests

of the patient. That her approach sometimes "isn't such a collaborative effort" with physicians, or even with her patients when she has determined "what [Marie] thinks they should have," is beside the point for Marie. She describes, for example, working with an elderly man who is "very proud and very stubborn and he doesn't want to admit that he is going to need help and he does need help" (p.8.L32-33). "And so I [spoke with his physician and] made it sound like the patient has recognised that he is weak" and willing to discuss plans for home care. Marie arranges for a meeting that afternoon that

> *turned out to be a very nice collaborative sort of four-way discussion with father, son, physician and nurse [that] turned out very nicely but I think if I had said to the physician "we have to look at some long term care or some short term care" without painting a real dismal picture that he would have [said] "no he's fine...we're giving him his chemo...we'll do this and let's not look at it for awhile." This particular physician doesn't want to admit he's going to be defeated on this one, and yet I know he's going to be defeated on this one.* (p.8,9.L.44-45,1-5)

Helen explains: "However much nurses want to do [what they believe is right or necessary] they can only go so far because it's the doctor who orders the medication and if you can't persuade the physician by, you know, giving him all sorts of information which he can verify ...you can't do anything" (p.6,L.19-22). She remembers the frustration of working in situations with only one physician, rather than with residents and interns; other options for obtaining orders for appropriate pain medication.

The "doctor nurse game," addressed once again in a recent edition of the AARN

Newsletter, has changed little since it was first described in 1967 (Hardingham, 1994). As Hardingham states, the traditional relationship between physicians and nurses has been dismissed by feminists as "oppressive" for women. Rather than playing games that "contribute to inefficient communication and hinder the open dialogue essential to ethical decision making" (p.12), Hardingham argues that nurses must demand collaboration. She places the problem squarely with nursing when she states that "nurses require better communication skills, higher levels of education, and that they should practice more like physicians in order to be seen as partners on a truly collaborative health care team" (p.13). I submit that the stories described by Marie, Lynn, Helen, and Sarah suggest quite the opposite. The ability of many nurses to endure the suffering of those for whom they care; to remain present, physically, emotionally, intuitively, and intellectually, becomes a standard by which many physicians would falter. That current working conditions remain hierarchical is an entrenched reality, representing the structure of many working, and indeed, many social environments. The participants in this study know this, and yet, in order to see that the right things are done for their patients, they are prepared to play whatever games are necessary. We cannot dismiss their actions; if we do, we risk losing a crucial aspect of the ethical care of those rendered vulnerable by illness.

On Suffering.

> Lerner (1978) writes of her husband's illness:
>
> While I myself was in it, a struggling, aching part of it, the need for comprehending what was happening was my only means of "distancing" myself, however badly I succeeded. The journal, the log, the diary, the

> poems all together reassured me of my roots in life, of my ability to stay out of the process sufficiently to survive. For all along a dark and terrible urge pulled me toward a total acceptance and sharing of his experience. I cannot say I ever wanted to die with him, rather it was that I felt I *was* dying with him and must save myself somehow. Why this was I do not know (p.264).

How do nurses keep from "dying" with each patient, when the patient has become more than a patient; has become a friend or "like a member of my family"? Helen writes:

> *I think one of the startling things that I found when I came to [this hospital] was how short the history was for some of these people. I mean some people, some of those patients, especially the leukemic ones... they started to feel sick last week and within a week they're [here] with a life-threatening diagnosis. I mean, the trauma for these people is just overwhelming... (p.7,L.38-42)*
>
> > *My attitude is [that] I like to be with the patients. I mean, I like doing bedside nursing. You're one with the patient and you spend all your time with them and when you're doing care [you] find out about them. (p.7,L.45; p.8,L.1-3)*

When asked how she handles that degree of closeness with her patients, Helen does not describe a formula or standard approach, nor does she describe tactics for distancing herself. Rather, she describes the value such closeness has for her. She notes that the patients become "a surrogate family in some ways. I've become very close to some of

them..." (p.8,L.6-7). "I'll take them home with me in my mind. Not all patients, but sometimes I'll get very close to somebody and it will be a terrible wrench when they go and that's sometimes hard to get over" (p.8,L.18-20). She remembers:

> *...we lost a patient a couple of weeks ago in the night, a very young woman that we'd all got very attached to because, you know, she'd been in and out for the last four years... and we were privileged... privileged to be there when she died because the closeness and support of her husband is something that I still can't talk about because I just break down and cry. You get so close. Maybe that's not good in one way but it is good in another because it's your humanity, your warmth, as you interact not only with the patient but the entire family and this involved her husband and a young child and a sister...well several sisters, I mean she was only 34. ...and she would say things...I understand she told... asked... one nurse to please make sure her husband married again - you know, to try and encourage him to remarry. You know, that's really hard when somebody comes out with something like that. The night before she died she wanted a sponge bath because she didn't think she'd be here tomorrow. You know, that's hard. This was a particularly hard death for all of us because we had become attached. But I don't think you become hard because of things like that. That happens every day. You're sad, and you pick up and go on because there is a lot more coming. But you know there are some that you become very attached to.* (p.8,L.24-42)

For Helen, there may be "hard deaths" and "hard times," but there is enough balance in her experience to keep from becoming "hard" or rigid in her encounters with patients. Helen describes touch as a way to facilitate closeness and communication with her patients. "I think an arm around a shoulder or a hand on an arm is very comforting. It is to me, and I use it [touch] a lot in my work" (p.8,L.9-10). She considers, as well, the advances in treatment that have afforded this woman four years of relatively good health.

Even in the most hopeless or devastating of situations, nurses usually have few options for metaphorically "leaving the bedside"; the intimacy of caring for and about another's most basic needs invites a connection most often reserved for one's most trusted companions. Helen discloses that staying by patients who have ruptured major arteries and are rapidly exsanguinating is particularly difficult. Sometimes, the best you can do, she explains, is to hold a hand and stay by their side. Yet this example is an obvious one as we search for illustrations of when it is most difficult to stand close to suffering. Such horrific stories of the deaths of patients are relatively few; it is the "ordinary" deaths, the passings of people we have administered chemotherapy to, taught and bathed and fed, comforted and cared for, touched and been touched by, that matter the most in our ability to endure.

"Emotional" responses to suffering are part of cancer nursing, as necessary as one's intellect or intuition. Rather than developing "habits of numbing or suppressing emotion," Callahan (1988) argues, "the care and cultivation of moral sentiment should be seen as all-important; after all, the rational tutoring of emotion depends upon people who already possess a highly developed emotional repertoire" (p.12). Held (1990) concurs, noting that

> [c]aring, empathy, feeling with others, being sensitive to each other's

> feelings, all may be better guides to what morality requires in actual contexts than may abstract rules of reason, or rational calculation, or at least they may be necessary components of an adequate morality. (p.332)

"I think we have the power and if we feel strongly enough we know how to get things done that we think ought to be done" (Helen, p.12,L.4,5). While knowledge of what to do and how to do it, along with the power to do things is vital, perhaps an even more essential facet of Helen's statement is "if we feel strongly enough". A key element in understanding the ethical or right thing to do must be one's "feeling" or emotional response to a situation.

In an earlier story, Helen chose to stand close to suffering during her shift with Bill as he sorted through his limited options for treatment. Bergum (1994) notes that "it is the [interaction of] both professional and patient where reduction of vulnerability and pain is made possible" (p.78). Does this include Helen's vulnerability and pain too? It is the relationship between Helen and Bill that generates vulnerability, and yet, paradoxically, the reduction of vulnerability in a manner that preserves Helen and Bill intact. Many of the stories told by the participants in this study address the issue of relationships. When we find ourselves asking "what is ethical about this," we must look to the relationship. When considering the difference between "good (technically expert) nursing care" and "ethical nursing care," I suggest that the strength or depth of the relationship, and the degree of differentiation between individuals within the relationship, will provide a clue.

Helen notes at one point that she thinks he made the `right' decision. What bearing does this have on her relationship with Bill, with her ability to stand close? We consistently

(and, I have argued, often unconsciously) take stock of what is going on around us, making sense and creating meaning in all that "shows up" for us in a day. What happens when things don't `add up' or people `fail' to react or behave as we expect them to? Would this be threatening to Helen in some way, perhaps leading her to distance herself, or leave, or to reduce Bill's experience to the category of `In Denial'? It can be difficult to stand by someone who clings to hope and to life beyond all possibility for more.

It is possible, of course, to be physically present, yet emotionally distant from the situation at hand. Marie notes that many physicians and nurses who lack experience in discussing difficult topics will revert to the "scientific language" that is "safe and comfortable" for them. Helen talks about "normalizing" for young doctors the feelings of sadness or grief that may arise when a patient dies; letting them know that it's "alright... to feel like that, that we too [feel] the same." She mentions a resident, a "very compassionate" young doctor with children of her own:

> *I can remember her going to see a young man with a melanoma and his wish was no further [treatment] ...a young man - 22... and he knew that he was dying and he wanted to go and die at his uncle's farm. We were all comfortable with that and he talked about it very openly and [the doctor] had gone in and she came out and she said... her eyes were filled with tears and she said "that young man really moves me, you know, that he could talk so openly at such a young age about..." and he died about 10-12 days later. So, he got what he wanted and I think she, as we, felt comfort that, you know, we'd done what we could for him and he didn't*

want any more chemo, he just wanted pain control and to go and die. He did that. (p.15,L.44-45;p.16,L.1-7)

Marie describes her particular manner of coping with loss: "if I can't let somebody go [and] they have been a big part of my life as a nurse... I don't have to and so I don't. ...I have four patients sitting on my shoulder. ...they're just there and I get great comfort from that" (p.12,L.36-42). Rather than fighting to keep people with her longer than they are capable, interfering with their own pace and timing of illness, Marie creates a space for them to remain with her on her shoulder. Some patients, for Marie, are "shoulder people"; others, in spite of her sadness or grief, she is able to let go.

"I am who I am because of the people...the patients I have met" (p.14,L.41-42), Marie explains. "Yes it's real tough. Every once in a while you just go "oh shit, I don't think I can do this - this isn't real - this can't be the real world." But it is the real world...[and the] part of it that I focus on is the beautiful part that comes out of it" (p.15,L.1-4).

Dissonance and resonance as clues to knowing and timing.

As Bergum notes (personal communication, May 13, 1994), there are many facets in the crystal that comprises "ethical practice," through which one may study experience. Within this study we have peered through only a few of the facets. Furthermore, the exploration has been conducted through my own lens, filtered by my years of oncology nursing practice. The concept of "dissonance" has been central to my experience of ethical understanding and growth. The Oxford Dictionary lists the meaning of dissonance as "harsh-toned, clashing". Change theory indicates that "unfreezing" is required for change

to occur and an experience of dissonance usually led to an unfreezing of my conception of right or wrong. Something wasn't right - I would feel it in my gut (visceral dissonance), or experience a brief rush of anger or dismay (emotional dissonance) before my brain was able to apply words to the experience.

Helen describes a case from early in her career that stands out for her and illustrates the notion of dissonance. Remembering a time "when I was first conscious of what I really felt was wrong," she recalls a young man of 32 returning from the operating room and the hushed tones of a medical fellow saying "open and close - nothing we can do". The parents were informed, but the doctors...

> *never did tell him - not in the hospital. And you know that was the first time, as a nursing student, that I... that felt wrong because he wasn't much older than me and... I would want to know. It sounds unreal now because we don't hesitate to tell the patients, but [back then] we did not tell. Any awkward questions... we just sort of changed the subject or tried to talk about something else.* (p.L.5-24)

Reading the words of the four study participants has frequently induced a sense of resonance with my own experience of practice. "Resonant" is defined as "echoing, resounding, continuing to sound; reinforced or prolonged by reflection or synchronous vibration." When I tune my guitar strings I know they have reached the correct tension when they reach a synchronous vibration with my tuning fork. But I have tried to go beyond resonance to hear with my "third ear," listening for more than what I already "knew". I have been searching not only for stories that resonate with my own, but even more for stories that challenged my understanding of what it means to be ethical. In the

process, learning has followed. Comprehension of the ethical experience of other nurses has led to a sense of harmony; "harmonious," meaning "tuneful--forming a pleasing or consistent whole; concordant." A more obscure definition of harmony reads: "A collation of parallel narratives." It is only from within the narrative, the unfolding relationship itself, that we can begin to comprehend our own meanings, let alone those of another. Understanding my own meanings and wishes as clearly as possible has become essential to my ability to hear over the "noise" of my own beliefs; to begin to know another as they present in their own particularity. Honouring this distinction is an essential first step in knowing the right thing to do.

Chapter 5: The Rhythm of The Patient or The Patient as an Algorithm?

Levine (1977) states:

> Ethical behavior is *not* the display of one's moral rectitude in times of crises. It is the day-by-day expression of one's commitment to other persons and the ways in which human beings relate to one another in their daily interactions. (p.846)

The nurses who participated in this study, Sarah, Lynn, Marie, and Helen, have told eloquent and compelling stories of day-to-day caring for people with cancer. They have described what it felt like when they "got it right" or "got it wrong" and how to stand close to the suffering of others or stand aside when being too close would interfere with the path of another. Related themes of "knowing" and "timing" emerged from their stories. It became apparent that an understanding of the rhythm and timing of a particular patient required knowledge that has rarely been formally taught or researched; these nurses attended to their emotional, intuitive, and visceral responses to patients, as well as their formal, "certain" intellectual knowledge. One wonders what the impact of the recent proliferation of attempts to reduce complex patient care situations to algorithmic decision paths, such as care maps, will be on nurses like Lynn, Sarah, Marie, and Helen. Will mapping the care of a patient interfere with knowing and timing? Will following these maps create a well-worn path of certainty and safety? What will this mean for ethical care, if ethical care is related to particularity?

The four nurses who participated in this study have told stories that attend to the particularity of each person within the relationship; the patient, the family, the physicians,

the nurses, and the support staff. For the sake of the patients in their care, they played the "doctor-nurse" game in order to facilitate and maintain necessary relationships. A key question that was not asked, and could be addressed in a future study, was how, and to what extent, did ethical relationships with colleagues, co-workers, and the institution contribute to the nurses' ability to maintain an ethical practice.

Ethical principles, as this study has shown, are insufficient "knowledge" for determining the right thing to do in most clinical situations. At best, they may provide additional information; at worst, they represent a template approach to ethical practice. Placed carefully over a narrative, aspects of any story can be nudged or prodded into one or another of the core principles (autonomy, beneficence, non-maleficence, and justice). But there is no clear agreement, no "objective" conception of what is `good', or `harm', or `justice'. What does autonomy really mean to people situated within a network of relationships? How do we "express our commitment to one another" in a manner that is respectful of both individual differences and needs, and the needs of the community? These questions may only be answered at particular times, within particular relationships. As previously noted, one cannot begin to "know" in an ethical way, outside of the relationship. Research that is directed toward understanding the nature of ethical relationships, in all of their complexity, is urgently needed. A current research study being conducted by Bergum and Dossetor (1992), employing a multidisciplinary approach for exploring an ethic of nurturance, represents one such investigation.

The purpose of this study has been to begin to comprehend the voice of practicing oncology nurses. Field and Morse (1985) state that phenomenological research, if well

done, should "challenge the reader to respond by saying `Yes, it is like this' or `No, I do not believe it is like that'" (p.27). Each reader of this study is invited to reflect on their own stories; to continue the dialogue and extend our understanding of the ethical practice of oncology nurses.

References

Alberta Association of Registered Nurses. (1987). Guidelines for bioethical decision-making in nursing. Edmonton, AB: Author.

Benhabib, S. (1987). The generalized and the concrete other: The Kohlberg-Gilligan controversy and feminist theory. In S. Benhabib & D. Cornell (Eds.), Feminism as critique on the politics of gender (pp. 77-95). Minneapolis: University of Minnesota Press.

Benner, P. (1983). Uncovering the knowledge embedded in practice. Image: The Journal of Nursing Scholarship, 15(2), 36-41.

Benner, P. (1985). The oncology nurse specialist: An expert coach. Oncology Nursing Forum, 12(2), 40-44.

Benner, P., & Wrubel, J. (1989). The primacy of caring: Stress and coping in health and illness. Menlo Park, CA: Addison-Wesley.

Benner, P. (1991). The role of experience, narrative, and community in skilled ethical comportment. Advances in Nursing Science, 14(2), 1-21.

Bergum, V. (1991). Being a phenomenological researcher. In J. Morse (Ed.), Qualitative Nursing Research: A Contemporary Dialogue (pp.55-71). Newbury Park, CA: Sage.

Bergum, V., & Dossetor, J. (1992). Toward a theory of an ethic of nurturance for health care. Research Project, University of Alberta, Edmonton.

Bergum, V. (1994). Knowledge for ethical care. Nursing Ethics , 1(2), 71-79.

Bishop, A.H., & Scudder, J.R. (1990). The practical, moral, and personal sense of

nursing: A phenomenological philosophy of practice. New York: State University of New York Press.

Black, B.P. (1993). Caring in hellish places. In M.M.Styles & P.Moccia (Eds.), On nursing: A Literary Celebration (pp.131-143). New York: NLN.

Bramwell, L. & The London Nursing Research Consortium. (1989). Cancer nursing: A problem finding survey. Cancer Nursing, 12(6), 320-328.

Brock, D.W. (1993). Life and death: Philosophical essays in biomedical ethics. Cambridge: University Press.

Broyard, A. (1992). Intoxicated by my illness: And other writings on life and death. New York: Clarkson Potter.

Callahan, S. (1988). The role of emotion in ethical decisionmaking. Hastings Center Report, 18(3), 9-14.

Canadian Nurses Association (1991). Code of ethics for nursing. Ottawa, Ont: Author.

Carper, B.A. (1978). Fundamental patterns of knowing in nursing. Advances in Nursing Science, 1, 13-23.

Cohen, M.Z., & Sarter, B. (1992). Love and work: Oncology nurses' view of the meaning of their work. Oncology Nursing Forum, 19(10), 1481-1486.

Cooper, M.C. (1990). Reconceptualizing nursing ethics. Scholarly Inquiry for Nursing Practice: An International Journal, 4(3), 209-218.

Cooper, M.C. (1991). Principle-oriented ethics and the ethic of care: A creative tension. Advances in Nursing Science, 14(2), 22-31.

Curtin, L.L. (1979). The nurse as advocate: A philosophical foundation for nursing. Advances in Nursing Science, 1, 1-10.

Davies, B., & Oberle, K. (1990). Dimensions of the supportive role of the nurse in palliative care. Oncology Nursing Forum, 17(1), 87-93.

Davis, A.J. (1989). Clinical nurses' ethical decision making in situations of informed consent. Advances in Nursing Science, 11(3), 63-69.

Davis, A.J. (1991). The sources of a practice code of ethics for nurses. Journal of Advanced Nursing, 16, 1358-1362.

Degner, L. & Western Consortium for Cancer Nursing Research. (1987). Priorities for cancer nursing research: A Canadian replication. Cancer Nursing, 10(6), 319-326.

DeWolf, M.S. (1989). Ethical decision-making. Seminars in Oncology Nursing, 5(2), 77-81.

Dzurec, L.C. (1989). The necessity for and evolution of multiple paradigms for nursing research: A poststructuralist perspective. Advances in Nursing Science, 11(4), 69-77.

Erlen, J.A., & Frost, B. (1991). Nurses' perceptions of powerlessness in influencing ethical decisions. Western Journal of Nursing Research, 13(3), 397-407.

Engelhardt, H.T. (1985). Physicians, patients, health care institutions - and the people in between: Nurses. In A. Bishop & J. Scudder (Eds.), Caring, curing, coping: Nurse, physician, patient relationships (pp. 62-79).

Alabama: The University of Alabama Press.

Field, P.A., & Morse, J.M. (1985). Nursing research: The application of qualitative approaches. Rockville, MD: Aspen.

Frank, A.W. (1991). At the will of the body. New York: Houghton Mifflin.

Fry, S.T. (1989). Toward a theory of nursing ethics. Advances in Nursing Science, 11(4), 9-22.

Gadow, S. (1980). Existential advocacy: Philosophical foundations of nursing. In T. Pence & J. Cantrall (Eds.), Ethics in nursing: An anthology (pp.41-51). New York: NLN.

Gadow, S. (1990). Response to "Personal knowing: Evolving research and practice". Scholarly Inquiry for Nursing Practice: An International Journal, 4(2), 167-170).

Gadow, S. (1992). Existential ecology: The human/natural world. Social Science Medicine, 35(4), 597-602.

Gadow, S. (1993, April). Women's health care: Social, medical, and ethical narratives. Paper presented to the Conference on Women, Health Care, and Ethics, Knoxville, Tennessee.

Gilligan, C. (1982). In a different voice. Cambridge, Mass: Harvard University Press.

Gilligan, C. (1987). Moral orientation and moral development. In V. Kittay & D.T. Meyers (Eds.), Women and moral theory (pp. 19-33). Rowman & Littlefield Publishers, Inc.

Griffiths, P. (1986). The thames and hudson encyclopedia of 20th century music. New York: Thames and Hudson.

Grout, D.J. (1960). A history of western music. New York: Norton & Company.

Hammond, M., Howarth, J., & Keat, R. (1992). Understanding phenomenology. Oxford: Blackwell.

Hardingham, L.B. (1994). Silence and collaboration in nursing. AARN Newsletter, 50(7), 12-13).

Held, V. (1990). Feminist transformations of moral theory. Philosophy and Phenomenological Research, 1(Supplement), 321-344.

Jameton, A., & Fowler, M.D. (1989). Ethical inquiry and the concept of research. Advances in Nursing Science, 11(3), 11-24.

Jansson, L. & Norberg, A. (1989). Ethical reasoning concerning the feeding of terminally ill cancer patients. Cancer Nursing, 12(6), 352-358.

Ketefian, S. (1991). Moral reasoning and ethical practice: An integrative review. New York: NLN.

Knaack, P. (1984). Phenomenological research. Western Journal of Nursing Research, 6(1), 107-114.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. American Journal of Occupational Therapy, 45(3), 214-222.

Leonard, V.W. (1989). A heideggerian phenomenologic perspective on the concept of the person. Advances in Nursing Science, 11(4), 40-55.

Lerner, G. (1978) A Death of One's Own. New York: Simon and Schuster.

Levine, M.E. (1977). Nursing ethics and the ethical nurse. American Journal of Nursing, 77(5), 845-849.

Levine, M.E. (1989). Beyond dilemma. Seminars in Oncology Nursing, 5(2), 124-128.

Lynch-Sauer, J. (1985). Using a phenomenological research method to study a nursing phenomena. In M.M. Leininger (Ed.), Qualitative research methods in nursing (pp. 93-107). Toronto: Grune & Stratton.

McKinnon, S. (1992). The ethical experience of nurses: An integrative review of selected qualitative research studies. Unpublished manuscript, University of Alberta, Edmonton.

Moch, S.D. (1990). Personal knowing: Evolving research and practice. Scholarly Inquiry for Nursing Practice: An International Journal, 4(2), 155-165.

Mooney, K.H., Ferrell, B.R., Nail, L.M., Benedict, S.C., & Haberman, M.R. (1991). 1991 oncology nursing society research priorities survey. Oncology Nursing Forum, 18(8), 1381-1388.

Moore, T. (1992). Care of the soul: A guide for cultivating depth and sacredness in everyday life. New York: HarperPerennial.

Munhall, P.L. (1983). Methodologic fallacies: A critical self-appraisal. Advances in Nursing Science, 4, 41-49.

Munhall, P.L. (1993). "Unknowing": Toward another pattern of knowing in nursing. Nursing Outlook, 41(3), 125-128.

Omery, A. (1989). Values, moral reasoning, and ethics. Nursing Clinics of North America, 24(2), 499-508.

Penticuff, J. (1991). Conceptual issues in nursing ethics research. Journal of Medicine & Philosophy, 16(3), 235-258.

Rilke, R.M., (1992). From: Letters to a young poet. In M.J. Moffat (Ed.), In the midst of winter (pp. 233-234). New York: Vintage Books.

Roy, D.J. (1989). Ethical issues in the treatment of cancer patients. Journal of Palliative Care, 5(2), 56-61.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. Advances in Nursing Science, 16(2), 1-8.

Sherwin, S. (1989). Feminist and medical ethics: Two different approaches to contextual ethics. Hypatia, 4(2), 57-72.

Slawson, D.C., Shaughnessy, A.F., & Bennett, J.H. (1994). Becoming a medical information master: Feeling good about not knowing everything. The Journal of Family Practice, 38(5), 505-513.

Smith, M.C. (1992). Is all knowing personal knowing? Nursing Science Quarterly, 5(1), 2-3.

Solzhenitsyn, A. (1969). Cancer ward. New York: Bantom Press.

Spreen Parker, R. (1990). Nurses stories: The search for a relational ethic of care. Advances in Nursing Science, 13(1), 31-40.

Tisdale, S. (1986). The sorcerer's apprentice: Medical miracles and other disasters. New York: Henry Holt and Company.

Tolstoy, L. (1886, 1960). The death of Ivan Ilych and other stories. New York: Signet Classics.

Van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. London, Ont.: Althouse Press.

Van Manen, M. (1991). The tact of teaching: The meaning of pedagogical thoughtfulness. New York: State University Press.

Watson, M.J. (1988). Nursing: Human science and human care. New York: NLN.

Watson, M.J. (1990). Response to "Reconceptualizing nursing ethics". Scholarly Inquiry for Nursing Practice: An International Journal, 4(3), 219-221.

Webster, D. (1991). Mental health: The politics of self-care. In R.M. Neil & R. Watts (Eds.), Caring and nursing: Explorations in feminist perspectives (pp. 117-135). New York: NLN.

Weston, L. (1979). Body rhythm. New York: Harcourt Brace Jovanovich.

Will, M.D. (1993). The hourglass effect: Living with cancer. Unpublished manuscript, University of Alberta, Edmonton.

Wolfer, J. (1993). Aspects of "reality" and ways of knowing in nursing: In search of an integrating paradigm. Image: Journal of Nursing Scholarship, 25(2), 141-146.

Yarling, R.R., & McElmurry, B.J. (1983). Rethinking the nurse's role in "do not resuscitate" orders: A clinical policy proposal in nursing ethics. Advances in Nursing Science, 5(7), 1-12.

Yarling, R.R., & McElmurry, B.J. (1986). The moral foundation of nursing. Advances in Nursing Science, 8(2), 63-73.

Yeo, M. (1989). Integration of nursing theory and nursing ethics. Advances in Nursing Science, 11(3), 33-42.

Zerwekh, J.V. (1990). A qualitative description of the competencies of expert public health nurses (Doctoral dissertation, Seattle University, 1990). Dissertation Abstracts International, 0569 TSZ.

The Meaning of Ethical Practice for the Oncology Nurse

CONSENT FORM

This consent form, a copy of which has been given to you, is only a part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose and Method

This research study is being conducted by a student in the Master of Nursing Program at the University of Alberta. The purpose of the study is reach an understanding of what an oncology nurse considers to be ethical nursing practice, and to explore what meaning ethical practice holds for the nurse. It is your own personal view of ethics that is important for this study. Although each nurse's experience will vary, the intent of this study is to examine the experience of six or seven nurses in depth. If you agree to participate, you will be interviewed by the researcher and the conversations will be tape recorded. From one to three interviews will be conducted by the researcher. Each interview will last about one to two hours. A time and place will be set for each interview that is convenient for you. You will be asked for detailed stories of your experience in caring for people with cancer. You will be asked to include stories of what it is like when you are able to care for patients in an ethical way. You will also be asked to describe times when it has been difficult, for whatever reason, to care for patients in what you consider to be an ethical way.

The researcher will search the stories for common themes, in order to reach an understanding of what it is like for nurses.

_____ Initial
_____ Date

You may be asked to review the early results of the study with the researcher during a second or third interview. You may withdraw information that you have previously agreed to share, and you may withdraw from the study at any time by asking the researcher to stop the tape recorder, or by contacting the researcher or co-supervisors at the phone numbers below. There will be no adverse consequences if you decide to withdraw.

Confidentiality

A number will be written on the interview tapes instead of your name. Only the researcher will know your name and which number was given to you. A secretary will listen to the tapes and make typed copies of them. The research supervisors may read the typed copies. Dr. Olson will not listen to the tapes, as she may be able to identify the voices of study participants. Dr. Bergum will be the only other person beside the secretary to listen to the tapes. These people will not know who you are and will not share the information with anyone. Tapes and transcripts will be kept in a locked filing cabinet during the study. Only the researcher will have a key. If you share the fact that you have been interviewed with anyone, your identity may become known at the Cross. While confidentiality is assured, anonymity is not. You will not be identifiable in any published or unpublished results. It is hoped that the stories that emerge from this research will be recognised by oncology nurses as "their" story, rather than the stories of any particular nurse. The tapes will be erased at the end of the study. The written information (transcripts) may be used for another study in the future. An ethics committee will have to give approval before this is done. Again, your name will not appear on the transcripts. Data must be kept for seven years, in a locked space, in keeping with the University of Alberta research regulations.

Risks and Benefits

This type of research may have certain effects on the people who

_____ Initial
_____ Date

agree to participate. You may feel some discomfort, anxiety, and self-doubt related to reliving and reviewing ethical dilemmas. If this occurs, you may choose to discuss your anxiety with either a counsellor from the Department of Psychology (Marilyn Hundelby, 492-0896), or with anyone from the Department of Nursing (May Kennedy, 492-8715, has specifically agreed to provide this service). While you may find some value in talking about your experiences, taking part in this study may be of no personal benefit for you. However, based on the results of this study, it is hoped that our understanding of the concerns of oncology nurses will be improved.

As with all research done in a clinical practice area, (including, for example, research conducted by social workers or psychologists), there is a requirement that directly unethical or unsafe practice be reported (such as ongoing patient abuse). This research study is intended to explore the meaning of ethics within daily practice, and not to uncover unethical practice. This will be discussed in detail as part of the informed consent process prior to the first interview. Either the study participant or the researcher (with the participant's full knowledge) would take the first step in reporting unethical practice, with the first step in the process being a discussion with the Director of Nursing. You are encouraged to ask further questions about what might be reportable in order to clarify this for yourself.

If you have any questions or concerns about this study, you are welcome to contact the researcher or research supervisors:

Researcher:

Sandy McKinnon, RN, BScN 432-7530 (home) 492-6676 (work)

Co-supervisors:

Dr. Karin Olson, RN 492-7751 (work)

Dr. Vangie Bergum,RN 492-6676 (work, 24 hr answering machine)

_____ Initial

_____ Date

Understanding of Participants:

My signature on this form indicates that I have understood to my satisfaction the information regarding my participation in the research project, and agree to participate as a subject. In no way does this waive my legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I am free to withdraw from the study at any time. My continued participation should be as informed as my initial consent, so I can feel free to ask for clarification or new information throughout my participation.

If at any time during the course of this study I feel that I have been inadequately informed of the risks or benefits, or that I have been encouraged to continue in this study beyond my wish to do so, I can contact the Thesis Committee Supervisors at the telephone numbers listed above.

I understand that Sandy McKinnon at 432-7530 will answer any questions that I have about the research project. A copy of this consent form will be given to me to keep for my records and future reference.

Name of Participant_____

Signature of Participant_____

Name of Witness_____

Signature of Witness_____

Name of Investigator_____

Signature of Investigator_____

Date_____

_____ Initial

_____ Date